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A critical analysis of the implementation of the right to work and employment in the national context of Germany and Portugal. Implications for Social Policy

Elisa Fiala

Orientadora: Prof.ª Doutora Maria Paula Pestana de Freitas Silva Faria de Campos Pinto

Tese especialmente elaborada para obtenção do grau de Doutor em Política Social

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Resumo

Em todo o mundo, as pessoas com deficiência enfrentam situações de desvantagem em todos os domínios da vida. Entre estas, incluem-se maiores níveis de pobreza, piores indicadores de saúde, níveis educacionais mais baixos, menor probabilidade de participação no trabalho e no emprego, remunerações menos elevadas, piores condições laborais e oportunidades mais reduzidas de progressão na carreira (World Health Organization 2011).

Como consequência desta posição social de desvantagem, as pessoas com deficiência constituem um grupo-alvo importante para a política social. Em muitos países, as políticas da deficiência abrangem áreas tão diversificadas como a saúde, segurança social, educação e emprego. Em geral, as políticas da deficiência dizem respeito à criação e implementação de leis, prorrogativas e proibições, acções estatais e estratégias de taxação que respondem a problemas e necessidades das pessoas com deficiência e das suas famílias (Pinto and Fiala 2015). Até aos anos 1970, o modelo médico da deficiência era o paradigma na base das políticas da deficiência. A preocupação central destas políticas era a prevenção, cura ou eliminação da deficiência e, sempre que tal não fosse possível, a assimilação do corpo e da mente das pessoas com deficiência às normas e estruturas dominantes. A responsabilidade do Estado, nesta abordagem, consiste no desenvolvimento e implementação de leis, políticas e práticas que promovem a segregação e reabilitação das pessoas com deficiência (Rioux and Fraser 2006; Tremain 2006). Desde a emergência do modelo social da deficiência, nos anos 1970, as políticas da deficiência têm sido crescentemente informadas por uma abordagem de direitos humanos. A responsabilidade do Estado e, por inerência, as abordagens políticas, alteram-se quando são guiadas por um entendimento sociopolítico da deficiência. Nesta abordagem, já não é a pessoas com deficiência que tem que ser curada, reabilitada ou assimilada em normas e estruturas hegemónicas, mas são estas que têm que se transformar para acomodar as necessidades das pessoas com deficiência. O direito das pessoas com deficiência a um acesso e cidadania igualitários torna-se um dos principais objectivos políticos.

Nos últimos anos, as abordagens de "workfare", que determinam quem tem acesso a um estatuto de cidadania, tornaram-se predominantes nas políticas da deficiência a nível supranacional e nacional (Abberley 2002). Em muitos países, os benefícios tradicionalmente atribuídos a pessoas com deficiência foram restringidos ou eliminados e a participação em medidas de "workfare" – a participação económica das pessoas com deficiência – tornou-se um pré-requisito para acesso a apoios sociais (Morris 2011; Soldatic and Chapman 2010; Owen and Harris 2012; Soldatic and Meekosha 2012; Bussemaker 2005a).

Um dos principais objectivos destes desenvolvimentos políticos é reduzir o "peso significativo" que os benefícios sociais, incluindo as prestações por deficiência, colocam nas finanças públicas (OECD 2010, 12), mas também são o reflexo da importância que o trabalho e o emprego assumem nas sociedades contemporâneas. De facto, a ligação entre a identidade e o estatuto ocupacional, apesar de não ser necessariamente uma experiência universal, tornou-se particularmente dominante nos Estados de bem-estar Ocidentais, em que a participação no mercado de trabalho representa um marco importante de valorização da identidade social (Beck 2001b; Galer 2012; Abberley 2002). Como consequência, aspectos que tendem a ser encarados como positivos, como os efeitos da ocupação e participação laboral sobre o bem-estar individual, raramente são problematizados, tanto na literatura genérica de Política Social, como na literatura sobre deficiência. Os decisores políticos afirmam, pelo contrário, que o emprego e estatuto ocupacional são elementos centrais para a participação plena dos cidadãos na vida económica, social e cultural. O direito ao trabalho é, assim, essencial para a realização de outros direitos humanos e forma uma dimensão inseparável e inerente da dignidade humana. O trabalho deve providenciar uma base de sustento para a pessoa e para a sua família e, quando livremente escolhido e aceite, pode contribuir para o desenvolvimento pessoal e reconhecimento social dentro da comunidade (United Nations 2012b; OECD 2010).

O presente estudo visa reflectir criticamente sobre a implementação do direito ao trabalho e emprego, tal como consagrado na Convenção das Nações Unidas sobre os Direitos das Pessoas com Deficiência, em Portugal e na Alemanha. Estes dois países divergem em diversos pontos: Portugal, por exemplo, é habitualmente classificado

como um Estado de bem-estar do Sul da Europa, em que a família é o locus primário de solidariedade e apoio social (Karamessini 2007; Ferrera 1996). Em contraste, a Alemanha, geralmente classificada entre os Estados de bem-estar conservadores (Esping-Andersen 1990), apresenta um nível elevado de proteção social e um sistema de benefícios generoso. Adicionalmente, ambos os países têm abordagens diferenciadas no que se refere à participação das pessoas com deficiência no mercado de trabalho. No entanto, Portugal e a Alemanha integram a União Europeia e foram afectados por legislação supranacional, como a Directiva Europeia relativa à Igualdade no Emprego ou a Estratégia Europeia para a Deficiência 2010-2020 ou, de forma ainda mais proeminente, pela Convenção sobre os Direitos das Pessoas com Deficiência (CDPD), que ambos os países assinaram e ratificaram. O objectivo do presente estudo é identificar como as diferenças e semelhanças entre estes dois países afectam as realidades das pessoas com deficiência. Para este efeito, é necessária uma estratégia de pesquisa dual, que integre tanto a análise de leis e políticas (o nível dos sistemas), como a monitorização de experiências individuais.

- Como foi o direito ao trabalho e emprego (CDPD) traduzido nas leis, políticas e programas nacionais, no contexto alemão e português?
- Como é que as pessoas com deficiência, na Alemanha e em Portugal, experienciam, na prática, a efectivação do direito ao trabalho e emprego?
- O que se pode aprender, a partir dos casos alemão e português, que permita informar desenvolvimentos políticos futuros nesta área, ajudando a avançar o direito ao trabalho das pessoas com deficiência na Alemanha, em Portugal e noutros contextos?

Enquanto as duas primeiras questões visam produzir conhecimento sobre a situação nos dois países, a terceira questão de investigação dirige-se à dimensão comparativa do estudo, procurando identificar boas práticas que possam influenciar desenvolvimentos políticos em ambos os países.

Enquadrando-se no âmbito da teoria crítica, este estudo inclui tanto uma análise crítica das molduras legislativas, documentos políticos e estudos de avaliação de

políticas, como uma avaliação crítica da situação de facto. Para recolher informação sobre a eficácia das leis, políticas e práticas existentes, foram conduzidas 38 entrevistas semiestruturadas aprofundadas com pessoas com deficiência residindo na Alemanha e em Portugal. Os resultados deste estudo indicam que alterações legislativas recentes, em ambos os países, fortaleceram uma abordagem da deficiência à luz de um modelo de direitos humanos – pelo menos, ao nível formal. Não obstante, o direito ao trabalho e ao emprego carece ainda de implementação plena. A análise crítica revela que a exclusão e discriminação com base na deficiência, no mercado de trabalho, é ainda generalizada. Enquanto na Alemanha o emprego apoiado aumenta o risco de a pessoa se sentir excluída ou de experienciar condições de trabalho pouco dignas, também possibilita uma resposta alternativa ao emprego, numa escala elevada, que não se regista em Portugal. Em Portugal, as pessoas com deficiência apresentam maior risco de desemprego e, devido à insuficiência de medidas de apoio, designadamente medidas de emprego de longa duração, as redes familiares e outras redes de apoio, são chamadas a compensar este défice, incluindo financeiramente. A análise comparativa sistémica apontou ainda que a interseccionalidade da deficiência com outros factores interfere com os resultados das políticas e medidas existentes. Enquanto a posição de desvantagem das participantes do sexo feminino parece ser um fenómeno transnacional, regista-se uma diferenciação binacional quando a idade dos participantes é tomada em consideração. Em suma, enquanto o sistema alemão providencia os melhores níveis de proteção para os cidadãos mais velhos com deficiência que ainda se encontram a trabalhar, as medidas portuguesas focam-se prioritariamente no acesso ao trabalho e emprego e, consequentemente, são mais benéficas para jovens com deficiência em busca de trabalho. Em ambos os países, no entanto, as pessoas com deficiências intelectuais ou psicossociais encontram-se na situação de maior desvantagem. Pesem embora as lacunas e obstáculos evidenciados, a análise revelou oportunidades de aprendizagem bilateral. As recomendações apontadas pelos participantes e a avaliação crítica das leis e políticas em vigor constitui uma fonte valiosa de apoio ao desenvolvimento de políticas futuras na área do emprego. Globalmente, a tese conclui que políticas sociais que apoiem a inclusão das pessoas com deficiência no trabalho e emprego criam estruturas económicas e sociais mais justas e igualitárias, não apenas para as pessoas com deficiência, mas para todos.

Palavras Chave: deficiência, Política Social, trabalho e emprego, direitos humanos, teoria crítica, cidadania, estudos comparativos, Portugal, Alemanha

Abstract

The present study critically reflects on the implementation of the right to work and employment as enshrined in the UN Convention on the Rights of Persons with Disabilities in Portugal and Germany and frames it within the wider scope of Social Policy. Including the narratives of disabled people themselves, the results of this study indicate that recent legislative changes in both countries strengthen a human rights approach to disability. However, the right to work and employment still lacks full implementation. The critical analysis reveals that exclusion from and discrimination in the labour market on the ground of disability is still widespread. Despite persisting gaps and obstacles, the analysis shows that there is scope for binational learning and presents recommendations for future policy development.

Keywords: disability, social policy, work and employment, human rights, critical theory, citizenship, comparative studies, Portugal, Germany

List of abbreviations

ADP - Associação Portuguesa de Deficientes
AMA - American Medical Association
BAG WfbM – Bundesarbeitsgemeinschaft für behinderte Menschen
BEM – Betriebliches Eingliederungsmanagement
BGG – Behinderungsgleichstellungsgesetz
BMAS – German Federal Ministry of Labour and Social Affairs
BTHG – Bundesteilhabegesetz
CAO - Occupational Activity Centres
CEDAW – Convention on the Elimination of All Forms of Discrimination against Women
CESCR – International Covenant on Economic, Social and Cultural Rights
CIL – Centres for Independent Living
CRC – Convention on the Rights of the Child
CRPD – Convention on the Rights of Persons with Disabilities
DIMR – German Institute for Human Rights
DRPI – Disability Rights Promotion International
ENDEF - Estratégia Nacional para a Deficiência
EU – European Union
FRG – Federal Republic of Germany
GdB – Grad der Behinderung
GDR – German Democratic Republic
GG – Grundgesetz
IAS – Valor do Indexante dos Apoios Sociais
IEFP - Instituto de Emprego e Formação Profissional
ICERD – International Convention on the Elimination of All Forms of Racial Discrimination
ICF – International Classification of Functioning, Disability and Health
ICIDH – The International Classification of Impairment, Disabilities and Handicaps
ICMW – International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families
IfS – Institut für Sozialforschung
ILO – International Labour Organisation
NGO - Non-Governmental Organisation
INR - Instituto Nacional para a Reabilitação
NS – Nationalsozialismus
ODDH - Observatório da Deficiência e Direitos Humanos
OECD – Organisation for Economic Co–operation and Development
SAPA - Sistema de Atribuição de Produtos de Apoio
SGB – Social Code Book
UDHR – The Universal Declaration of Human Rights
UK – United Kingdom
UN – United Nations
UPIAS – The Union of the Physically Impaired Against Segregation
WfbM – Werkstatt für behinderte Menschen
WHO – World Health Organisation

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Introduction

> "The changes that will make a better society for people with disabilities to live in will make a better society for everybody to live in" (Sutherland 1981, 12)

According to the World Report on Disability (World Health Organization 2011), there are about one billion people living with some kind of disability worldwide. People with disabilities are the world's largest minority group; they make up around 15% of the world's population. The World Report on Disability illustrates that disability is further on the rise due to ageing populations and the higher risk of disability in older people as well as the global increase in chronic health conditions (World Health Organization 2011, xi). Across the world, people with disabilities find themselves in a disadvantaged position in all life domains; they have higher rates of poverty and poorer health outcomes, they have generally lower education achievements and are less likely to participate in work and employment and even when economic participation is achieved, people with disabilities are likely to be employed in low-paying jobs with poor working conditions and promotion opportunities (World Health Organization 2011).

As a consequence of their disadvantaged social position, disabled people are an important target group of social policy. In many countries, disability-specific policies exist addressing different areas, such as health, social security, education and employment. In general, *disability policy* refers to the creation and implementation of laws, entitlements and prohibitions, State actions and taxation strategies that address issues and the needs of persons with disabilities and their families (Pinto and Fiala 2015). The English Poor Law of 1601 can be seen as one of the first public policy documents targeting persons with disabilities. The law was introduced to distinguish the 'worthy" from the "unworthy" poor, those considered incapable of engaging in work from those who were unwilling to do so, and therefore were considered no proper objects of pity and charity (Oliver and Barnes 2012; Bickenbach 2012).

Although disability as a social category has been addressed by social-policy makers earlier, it was not until the middle of the twentieth century - after two World Wars – that the demand for disability-specific legislation became a political priority in many

countries, due to increasing numbers of injured war veterans (J. Campbell and Oliver 1996). Up until the 1970s, the central concern of newly introduced disability policy was rehabilitation, underlined by the assumption that persons with disabilities who could be enabled to participate in the labor market could become 'tax producers rather than tax consumers' (Bickenbach 2012; Poore 2007; J. Andersen and Perry 2014). In recent years, workfare approaches that determine who is entitled to citizenship status, have become predominant in disability policies on supranational and national levels (Abberley 2002). In many countries, traditional disability benefits have been restricted or cut and the participation in workfare measures – the economic participation of disabled people - has become a perquisite to receive social entitlements (Morris 2011; Soldatic and Chapman 2010; Owen and Harris 2012; Soldatic and Meekosha 2012; Bussemaker 2005a).

One of the aims of these policy developments is to minimise the "significant burden" that social benefits, including disability benefits, place on public finances (OECD 2010, 12), but they also reflect the importance that work and employment have attained in contemporary societies. In fact, the connection of identity with occupational status, although not necessarily a universal experience, has become particularly dominant in Western welfare states, in which the participation in the workforce marks an important feature of the valued social identity (Beck 2001b; Galer 2012; Abberley 2002). In consequence the assumed positive aspects of employment and occupation on individual well-being are hardly questioned in both mainstream and disability-specific frameworks (see, for example, the European Disability Strategy 2010–2020 or the Employment Equality Framework Directive). Policy makers claim, instead, that employment and occupation status are key elements that contribute to the full participation of citizens in economic, social and cultural life. The right to work is thus essential for the realisation of other human rights, and forms an inseparable and inherent part of human dignity. Work is meant to provide livelihood to the person and her or his family, and if work is freely chosen or accepted, it contributes to the person's personal development and social recognition within the community (United Nations 2012b; OECD 2010).

Despite an increasing focus on the participation in work processes, national and international surveys show that people with disabilities belong to the most marginalised in present labour markets (Burchardt 2000; International Labour Organisation 2004; OECD 2010; World Health Organization 2011; United Nations 2012b; Sainsbury 2017). Moreover, the employment gap between disabled and non-disabled people has been further increasing in recent years (United Nations 2012b; World Health Organization 2011). A recent OECD report, for instance, shows that across all OECD countries employment rates of people with disability are significantly below the overall average, and that unemployment rates are typically double (OECD 2010, fig. 1.2). Furthermore, studies found that people who become disabled while in work are more likely to lose their employment during the first year after the attained disability, and that disabled jobseekers have greater difficulties in finding a job than their non-disabled counterparts (Burchardt 2000).

Although numerous studies focus on the connection between employment and disability (United Nations 2012b; International Labour Office 2007; OECD 2010; Burchardt 2000; Waddington 1995; Boman et al. 2015; Kim 2010; Sainsbury 2017; Thornton and Lunt 1997; Visier 1998), the issue requires further investigation. International studies offer general recommendations, however they often lack country specific information (United Nations 2012b) or the results are outdated (Thornton and Lunt 1997; Visier 1998; OECD 2010). In addition, comparative international studies often focus on the *de jure* situation and thus lack an emphasis on the *de facto* reality of disabled people's everyday lives. In general, too, there is a shortage of studies that are embedded within critical approach and that include the perspectives of disabled people themselves.

By providing research that is framed by the human rights approach, and places emancipation and the narratives of disabled people on its agenda, this study will start to address this gap. The present study contributes to the field of comparative disability studies, a research area that is quickly emerging (see for example the DISCIT project[1]).

[1] DISCIT project ran from February 2013 to January 2016. DISCIT aimed to produce new knowledge to enable Member States, affiliated European countries and the European Union to achieve full and effective participation of persons with disabilities in society and the economy. For more information

The study is unique in the sense that there is currently no research available that compares the labour market participation of disabled people in Germany and Portugal in-depth. The critical analysis of law and policy and of the stories collected provide valuable recommendations for the further development of social policies in Portugal and Germany.

The aim of the research

The present study aims to critically reflect on the implementation of the right to work and employment as enshrined in the UN Convention on the Rights of Persons with Disabilities (CRPD) in Portugal and Germany. Portugal and Germany are two countries that differ in various points: Portugal, for instance, is usually classified as a Southern welfare state in which the family is the primary locus of solidarity and social support (Karamessini 2007; Ferrera 1996); In contrast, Germany is in general classified among the conservative welfare state regimes (Esping-Andersen 1990) with a high level of social protection and a generous social entitlement system. In addition, both countries have different social policy approaches when it comes to the labour market participation of disabled people. Portugal and Germany, however, belong to the European Union and both countries have been influenced by supranational legislation, such as the European Employment Equality Framework Directive or the European Disability Strategy 2010-2020, and most prominently by the international disability human rights framework which both countries signed and ratified. The aim of the present study is to identify how the differences and similarities between both countries affect the realities of disabled people. For this purpose, a dual research strategy is necessary that includes both the analysis of law and policy (the system's level) and the monitoring of individual experiences. The following research questions guide this study:

- How is the right to work and employment (CRPD) translated into national laws, policies and programmes in the German and in the Portuguese context?

see https://blogg.hioa.no/discit [date of last access 27/09/2018].

- How do people with disabilities in Germany and in Portugal experience the fulfilment of the right to work and employment in practice?

- What can we learn from the German and Portuguese cases to inform future policy development in this area that advances the right to work for people with disabilities in Germany, Portugal and beyond?

While the first two questions aim to produce knowledge about the situation in both countries, the third research question addresses the comparative aspect of the study and the aim to *identify best practice policies that can influence future policy development in both countries*.

Embedding the project within critical theory, the study includes both a critical analysis of legal frameworks, policy papers and evaluation studies and a critical evaluation of the *de facto* situation. To gather information about the effectiveness of existing laws, policies and practices, 38 semi-structured in-depth interviews with persons with disabilities living in Germany or Portugal have been conducted. The results of this study indicate that recent legislative changes in both countries strengthen a human rights approach to disability - at least on the paper. However, the right to work and employment still lacks full implementation in practice. The critical analysis reveals that exclusion from and discrimination in the labour market on the ground of disability is still widespread. While in Germany sheltered employment increases, on the one hand the risk to feel excluded and to experience undignified work conditions, it also provides an alternative form of employment which does not exist at a similar scale in Portugal. In Portugal, disabled people seem to have a higher risk to end up unemployed and due to the shortage of long-term and insufficient support measures, family and kinship relations have to compensate and support them (including in financial terms). In both countries, however, people with intellectual and psycho-social disabilities are the most disadvantaged. Despite all persisting gaps and obstacles, the analysis shows that there is scope for binational learning. The recommendations made by the participants and the critical assessment of the laws and policies in place provide a valuable source for the future development of disability employment policies. Overall, the thesis concludes that social policies that support the

inclusion of disabled people in work and employment create more just and equal economic and social structures, not only for people with disabilities, but for everyone.

Chapters outline

The first Chapter illustrates the nexus between the divergent theories of disability and social policy. Embedding the research within critical disability theory, first the roots of critical social theory are outlined. Then it is shown how critical disability scholars and activists have, since the emergence of critical disability studies changed the way disability is dealt with in academic and political discourses (J. Campbell and Oliver 1996; Bickenbach 2012; Rioux 2002; Barnes 2003b).

Chapter two outlines the emergence and the purpose of the international disability rights framework. It is illustrated that disability human rights provide a powerful tool for disabled people in their struggle to achieve equal citizenship status. Although the Convention does not implement any new rights, it clarifies the obligations States have to identify and adapt discriminatory and oppressive social structures that restrict persons with disabilities from fully enjoying all human rights and fundamental freedoms as defined in the International Bill of Human Rights. In addition, the monitoring obligation of the Convention is a powerful tool for disabled people, their families and supporters, to analyse the *de facto* situation and ensure the substantive effectiveness of the Convention (Lindqvist 2004).

Chapter three illustrates that the ontologies of work and employment have changed. Determining who is entitled to citizenship status, workfare approaches have recently become predominant in social policy approaches including social policies that address disabled people. It will be shown that workfare measures often fall short in the context of disabled people, a group that belongs to the most marginalised in the labour market. Critical disability scholars thus call for a radical transformation of the ontologies of work and employment (Abberley 2002; Soldatic and Chapman 2010; Becker 2015).

The critical review of the research literature paves the way to the methodology of the study which is outlined in chapter four. Taking a critical theory perspective, it is

shown that to fully understand the human rights status of disabled people in a particular society, it is not sufficient to analyse the *de jure* situation, but it is also necessary to include the experiences and narratives of disabled people themeselves. The research process is thus dualistic and includes both documental analysis of existing legislation, policies, programmes, and practices and semi-structured in-depth interviews with 38 persons with disabilities living in Germany and Portugal.

The results of the dualistic monitoring process are analysed in chapters five to seven. In Chapters five and six, it is first illustrated how national employment policies addressing disabled people have emerged historically in the two countries. It is further shown how the national social policies addressing the labour market participation of disabled people have been shaped recently by supranational trends and developments. Then, chapter seven complements the critical monitoring process by outlining the results gathered from the in-depth interviews. The results indicate that despite similar policy approaches in recent years, the lived experiences in Portugal and Germany differ. In both countries, however, obstacles and barriers in the area of work and employment still persist.

The systematic comparative analysis, undertaken in chapter eight, outlines how the intersectionality of disability interferes with the outcomes of the policies and measures in place. Based on the systematic analysis and the recommendations the participants made throughout the interviews, future policy directions and promising disability employment policies are outlined.

The thesis concludes discussing implications of this research for future social policy development. In the present world of work, which promotes individual productivity and capitalist norms, social policies are necessary to facilitate economic support and implement social policies that support the employment of disabled people. Looking at the world of work through the lens of disability requires a new vision in which values generally associated with waged labour such as independence, self-reliance, productivity and mainstream work arrangements are altered. It is stressed that social policies that support and accommodate more just, equal and inclusive ontologies of

work not only increase the inclusion of people with disabilities, but provide new and more inclusive perspectives for all of us.

1 Critical social theory and disability

The present research uses critical disability theory as a theoretical framework, as it is generally claimed that critical disability theory offers a theoretical framework to challenge neoliberal norms and values that have kept people with disabilities as one of the most oppressed groups in society (Devlin and Pothier 2006; Welti 2005; Hosking 2008). To gain an understanding of critical disability theory, the first section of this chapter provides an insight in its theoretical foundations. The most distinctive features of critical theory and the scholars who most influenced the present approach are explored. Then the link between critical theory and citizenship discourses is discussed before showing the influence of critical theory on disability studies. The chapter will proceed with an outline of the changing theories and models of disability. It will be shown that theory matters, as the conceptualisation of disability has an impact, not only on the understanding of the meaning of disablement, but also on the emergence of particular laws, policies and practices (Rioux and Fraser 2006).

1.1 Critical social theory

> "Theory with practical intent seeks not only to understand the world but also to transform it. The practical intent of such theory - its orientation to changing the world - is the expression of an emancipatory vision" (Alway 1995, 2).

Critical theory evolved from the work of scholars attached to the Frankfurt School. In contrast to traditional theory, critical theory condemns the theoretical character of social science and suggests an epistemological approach that has a practical, emancipatory interest (Habermas 1971; Berilsson 2000; Outhwaite 2000). Critical theory, in opposition to traditional theory, does not claim that it is normatively objective. The purpose of critical theory is to transform society with the aim of human emancipation. Hence, emancipation is a cornerstone of critical theory. As Craib outlines, the Frankfurt theorists were concerned with "the way the system dominates: with the ways in which it forces, manipulates, blinds or fools people into ensuring its reproduction and continuation" (Craib 1992, 185)[2]. The term "Frankfurt School"

[2] The Frankfurt school emerged in Germany at the beginning of the 20th century, in a place and at a time in which Fascism thought steadily grew and finally hold the power. In the years before the Second World War, social Darwinism and eugenic world views become dominant in Germany. From 1933 until

primarily describes the group of social researchers and philosophers that worked together under the directorship of Max Horkheimer (1895-1973) at the Institute of Social Research (Institut für Sozialforschung (IfS)). At the beginning of the 1930s, the Institute was established in Frankfurt/Main in Germany. While during its first years, under the directorship of Carl Grünberg (1861-1940), an Austrian historian and economist, the work of the Institute was mainly historically oriented and focused on the labour movement, socialism and economics, Max Horkheimer who became the second director in 1930 introduced a new direction which was grounded on an interdisciplinary, materialist, social research program. Due to the rise of power of the Nazi regime, Horkheimer and other members of the IfS emigrated via Genève to North America in 1935 where the institute was hosted at the Columbia University in New York City. In Europe, and later in America, the aim of the collaborative, interdisciplinary work was to elaborate a theory on the relation between the economy, psychology and culture of the contemporary capitalist society (Held 1980, 175). The joint theoretical framework was grounded in Marxism and Freud's psychoanalysis (Ramsay 2000; Alway 1995). Only later the work of the group was labelled as *critical theory* or *critical theory of society*. The term was first introduced by Max Horkheimer in his paper "Traditional and Critical Theory" (Horkheimer 1975).

Criticizing capitalism, Horkheimer claimed in September 1939, shortly before the outbreak of the war, that the one "who does not wish to speak of capitalism, should also be silent about fascism" (Horkheimer 1939, cited in Ramsay 2000, 144). Horkheimer further concluded in his research that the transition of liberal capitalism[3] into monopolistic capitalism[4] offered the possibility for authoritarian regimes such as German National Socialism to emerge (Ramsay 2000, 149). In his later works, Horkheimer restated his idea and stressed that a united movement of workers and intellectuals could be initiating a radical social change:

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the end of the World War II, the National Socialists took power over Germany. Under the leadership of Adolf Hitler, they established a dictatorship and enforced their Nazi eugenics with the ultimate goal to improve the Aryan race.

[3] Liberal capitalism describes capitalism in a liberal era with free market competition.

[4] Monopolistic capitalism describes the concentration of the ownership of the means of production in fewer and fewer hands.

> "Marxist categories of class, exploitation, surplus value, profit, pauperization, and breakdown are elements in a conceptual whole, and the meaning of this whole is to be sought *not in the preservation of contemporary society but in its transformation into the right kind of society*" (Horkheimer 1975, 218, own emphasis).

Returning to Germany after the world war, Horkheimer was confronted with the absence of proletarian revolutionary consciousness, a growth of monopoly capitalism and the expansion of the authoritarian state. As a consequence his work underwent numerous alterations. Whereas in Adorno´s later work a faint hope for a better world remained, Horkheimer's later work became greatly influenced by theological traditions and lapsed into pessimism (Held 1980, 198; Alway 1995, 49)[5].

In a joint effort with Theodor W. Adorno (1903-1969), a close friend and fellow scientist, Horkheimer wrote the most famous work of the Frankfurt School: the *Dialectic of the Enlightenment.* The work emerged between 1942 and 1944 while both, Horkheimer and Adorno, were living in exile in Los Angeles. In this work they interrogate the 'self-destruction [Selbstzerstörung] of the Enlightenment' (Horkheimer and Adorno 2006). As Ramsay outlines "read from a philosophical angle, The Dialectic of Enlightenment is a critique of reason, but a critique of reason with its own means, a self-reflection of enlightenment (Ramsay 2000, 151). Adorno and Horkheimer claim that the aim of enlightenment thought is the 'disenchantment [Entzauberung] of the world' (Horkheimer and Adorno 2006, 9). As Horkheimer, Adorno returned to Germany after the war. Adorno´s work influenced several generations of students and he became the one who personified the critical theory of society (Ramsay 2000, 153). In his work Adorno questioned - like Horkheimer - what hinders people from becoming conscious about themselves as subjects, capable of spontaneity and positive action (Held 1980, 51). In one of his most influential works "Minima Moralia" Adorno argues

[5] Craib argues that the pessimistic worldviews of the scholars of the Frankfurt School can partly be explained by looking at the world and time in which writers like Adorno and Horkheimer lived. The rising of Stalin and Hitler and the horrors that came with it greatly influenced their work. After the Second World War the negative impacts on society and social structures continued in form of capitalism, which further destroyed centuries of culture (Craib 1992).

that a truly emancipated society would be "the realization of universality in the reconciliation of differences"; such a society would be one in which "people can be different without fear" (Adorno 1951, 102). As Always illustrates Adorno's utopia of a “better world” is one in which “differences, distinctions, distances, and tensions—between people and between humankind and its environment—are regarded as normal and necessary, are defended and even celebrated” (Alway 1995, 69).

Today, Jürgen Habermas is one of the most far-reaching and discussed social theorist who belongs to the young generation of the proponents of ‘critical theory’. Habermas sees the history of mankind as an imperfect and distorted dialogue due to oppression and power relations. In his conception, language facilitates reflection and critique. Therefore the task of critical social science is to examine if consensus about norms, beliefs and ideas is justified rationally and is in line with universal interests, or if it is rather an expression of open or covert coercion, and thus revealed as the result of illegitimate power relations (H. Andersen 2000, 330). Habermas’ theory of the role of law in modern constitutional States becomes central in understanding how consensus, obtained communicatively, is to be transformed through political actions. In his work “Between Facts and Norms“ [*Faktizität und Geltung*] he claims that there is an internal connection between the development of law and democratic systems. Law is the medium that can transform communicative power[6] into political-administrative steering power. Facticity is the given condition at a given time, whereas validity is that which can be substantiated in a rational discourse (H. Andersen 2000, 337). Habermas claims that the modern concept of rights fills the ‘functional gaps’ opened when other mechanisms of social integration are overburdened (Habermas 1996, 318). For example, in modern capitalist societies in which paid work is an important distinction of a valued social identity, many social groups, such as people with caring responsibilities and people with disabilities are disadvantaged or excluded from the labour market. Thus politics and rights that support and strengthen the employment of such disadvantaged groups fulfil an important task to ensure that they are socially

[6] Habermas borrowed the key concept of “communicative power” from Hannah Arendt, who described it as a “freedom instituting power”, exemplified by democratic revolutions. It stems from the ability “not only to act, but to act in concert”, as opposed to violent and oppressive power (H. Andersen 2000, 338).

integrated and able to participate in social structures that contribute to a valued social identity. Habermas further argues that human emancipation is inevitable, not only for social change but also for the justification and legitimisation of existing laws and policies. The tension between norms and facts can only be solved by communicative actions that involve the various perspectives of individuals that are affected by those laws and policies (Habermas 1996).

1.2 Critical social theory and citizenship discourses

As critical social theorists are concerned with relations of power and oppression in contemporary societies it is a valid question to interrogate how do they understand the concept of citizenship? Introducing a reflexive account, Habermas suggests a definition of citizenship as a “minimal shared identity” (Beckett 2005, 417–18). In Habermas’s approach, such a minimal shared identity is reached through processes of reflexive engagement of free and equal citizens that aim to reach an understanding of which “goals and norms lie in the equal interest of all” (Habermas 1996, 270). The status of "free and equal members" takes a particular role. It is expressed in the autonomy that citizens have to form mutually acceptable laws and live under them. In such an approach citizens are seen as both: (1) authors of the law - through political participation citizens are enabled to shape and further define the rights - and (2) addressees – subjects - of the law. Habermas claims that rights anchor the status of "free and equal members” (Olsen 2011, 143). These rights can be defined in three functional categories that specify the status of a participant in deliberations: (1) rights to equal liberties as a subject of the law, (2) rights defining membership in a political community, typically the status of citizen, (3) rights to assert claims that one's rights have been violated and to have these violations remedied. In Habermas´s account, these rights establish a system of law in which the members of a society are recognised as legal subjects, who are granted freedoms of various kinds and who have legal remedy when their freedoms are violated. Going one step further, Habermas acknowledges that these rights are not in themselves democratic; two further categories are needed that focus on the political capabilities of citizens. Citizens must have (4) rights giving them equal opportunities to participate in the political processes, and finally, citizens must have (5) rights to the material circumstances needed to meet

equal opportunities (Habermas 1996, 121–32). In doing so, Habermas's reflexive account on citizenship recognizes issues that Marshall's social-liberal citizenship theory is lacking: that democratic politics often occur in economic and social circumstances in which some members of a society have better opportunities to participate in the political processes than others.

Indeed, T.H. Marshall's analysis of social class and citizenship has been one of the most influential in citizenship discourses and the most dominant approach to citizenship in the post-war era. It is almost inevitable to mention his social-liberal theory when discussing citizenship and the welfare state as his theory is the touchstone for much contemporary debate. In his essay "Citizenship and Social Class" Marshall divided citizenship in three elements: *social*, *civil* and *political.* He claimed that the three types of rights emerged in different moments of human history: Civil rights came first in the eighteenth century, followed by the extension of political rights, which was one of the main features of the nineteenth century. In contrast to civil and political rights, social rights played no significant role in the eighteenth and nineteenth century, their revival only began in the twentieth century with the emergence of public elementary education (T. H. Marshall 2009). Marshall claimed that while in Feudal societies, 'status' was the hallmark of class and the measure of inequality, 'citizenship' replaced the feudal 'status' in modern societies. Nowadays, the citizenship status determines the conditions for full social membership.

Marshall's social theory has been subject to much contemporary criticism (see Bussemaker 2005b; Mullard 2005; Cattacin et al. 2005; Beckett 2005), in particular as his image of the 'ideal citizen' or 'good citizen' is based on a male, white, able-bodied, breadwinner model and, thus, the majority of individuals, including disabled people, are excluded. Marshall's liberal theory thus legitimises, rather than reduces social inequality. As Young and Quibell claim in such approach rights do nothing but reinforce the status quo (D. Young and Quibell 2000, 757).

In Habermas's approach, in contrast, the last two categories of rights - the rights giving citizens equal opportunities to participate in the political processes (4) and the rights to support material circumstances needed to meet equal opportunities (5) – are

designed to redress this problem by equalizing differences in material circumstances that contradict people's political participation of civil freedom. Habermas considered material equality as lying on the heart of equality between democratic citizens (Olsen 2011, 143–46). In his citizenship approach, the State becomes necessary as a sanctioning, organizing, and executive power (Habermas 1996, 134), but citizens themselves are enabled through political participation to shape and further define their rights.

Whereas class - as a human distinction - has been almost routinely considered in citizenship discourses, disability and the perspective of disabled people have long been excluded from public debates about equal citizenship status. Only recently, in the emerging field of disability studies, the nexus between disability and citizenship status has been explored (Beckett 2005; Rioux 2002; Hosking 2008).

1.3 Disability studies and the conceptualisation of disability

Disability studies emerged as a new area of academic research and professional training in Great Britain and the North America in the 1970s and have since then further expanded across the globe (Pfahl and Powell 2014; Meekosha and Shuttleworth 2009). Initially, disability studies focused on the division between "impairment" and "disability" and challenged traditional models of disability. To understand the meaning of critical disability theory for the present research, the paradigm shift that occurred within disability studies needs to be understood. Thus the following outlines the recent paradigm shift and the changing concepts of disability.

1.3.1 The individual or medical model of disability

Since the 19th century, disability has been perceived according to so-called medical or individual classifications. In the *medical model of disability*, disability is classified in terms of deviance, lack and tragedy (Corker and Shakespeare 2002, 2) and thus it is assumed that the disabled person's functional ability deviates from that of his/her non-disabled counterparts – the "normal human body"[7] (Edwards 2000, 35). Within the medical model the 'problem' of disability is located within the person (Johnson

[7] In the era of modernity, meta-narratives that are built on an operational code of binary, 'either/or' thought, were central (Corker and Shakespeare 2002).

2009, 191). Such traditional individualistic approaches to `disability' highlight the ways in which the medical conditions constrain the daily lives of disabled people. In the medical model people with disabilities are perceived as dependant individuals who have to be helped, treated and normalised[8] (Linton 1998; Oliver 1996; Barnes 1990). Experts, such as practitioners, therapists or social workers, are in power and aim to eliminate, cure or where this is not possible manage the illness or disability (Tremain 2006, 186). Rehabilitation and the segregation in special institutions became the dominant response to disability. Oliver describes the predominance of medical professions and "pseudo-professions" as a medical "colonisation of disabled people's lives" (Oliver 1996, 33–37). From an epistemological perspective, the medical model is aligned with the positivist paradigm and underlies an individual approach, arguing that any disability can be described through objective medical knowledge[9] . Any kind of impairment can be discovered and treated through standardised scientific techniques such as diagnoses, medical tests and therapies (Rioux and Fraser 2006, 49–51). Within these kinds of epistemologies, that fail to take into account wider aspects of disability, disability is considered as a 'thing of shame' (Oliver 1990, 34). Disabled people are obliged to overcome their disabled status or, wherever this is impossible, conform as closely as possible to rigid norms of health and secure their own economic future[10].

[8] For a more detailed analysis on the social creation of dependency see (Barnes 1990; Sutherland 1981). Sutherland criticises the whole concept of `charity': both in the form of institutionalised charity and in everyday personal treatment of people with disabilities as passive recipients of other people's need to feel useful. A charity approach operates on a dependency model in which disabled people depend on the bountiful providers and experts. He further argues that the paternalism of charities can be compared to that of colonialism: "Oppression commonly produces ideologies to justify itself, claiming that it is helping those whom it keeps in a state of dependence... charities, while playing a major part in maintaining our dependent role, propagate the belief that we are helpless and, without their existence, would be even worse off than we already are" (Sutherland 1981, chap. 8).

[9] Based on feminist contributions Conrad and Baker show that rather than being value-neutral, some medical knowledge shores up the interests of those groups in power and thus sometimes reflects and reproduces existing forms of social inequality (Conrad and Barker 2010).

[10] Talcott Parsons provided the primary stimulus to sociological approaches to chronic illness and disability (Varul 2010). Parsons treated individual `health' as central to effective task performance and the overall well-being of contemporary (American) society. Although Parsons has tailored the sick role to American achievement values, it can be argued that is applies to other capitalist societies to the extent that liberal labour and consumer markets are the central loci of social exchange (Varul 2010). As formulated by Parsons, the sick role includes both responsibilities and privileges. Thus, the sick person is not held responsible for their condition, and is granted exemption from fulfilling their `normal' social obligations. In return, the sick person is required to take all appropriate steps to ensure their recovery, including consulting a medical practitioner (Barnes and Mercer 1996, 13).

Influenced by other social movements, such as the women´s movement or the gay and lesbian rights' movements, and as reaction to the dominant individual understanding of disability and the dominance of health professionals in their daily lives, disabled people and their supporters on both sides of the Atlantic formed a new consciousness about disability in the late 1970s (Oliver and Barnes 2012). This new consciousness marked the birth of the social model of disability.

1.3.2 The social model of disability

The new 'socio-political perspective' of disability marked a significant paradigm shift (Kuhn 1970) in disability discourses (Oliver and Barnes 2012; Oliver 1990). Paul Hunt provided an early illustration of this socio-political approach to disability. In his book `Stigma: The Experience of Disability', which appeared in 1966, he outlined that the prevailing norms of society are challenged by disabled people since they are not able to contribute to the economic good of the community (Hunt 1966). Hunt argued that disabled people's special position is a 'challenge' to ordinary society. The special position of disabled people is marked by five aspects commonly associated with disability, which are: disabled people are perceived as *unfortunate, useless, different, oppressed and sick*. Looking at the special situation of disabled people in society, he argued that the problem of disability lies not only in the impairment but in the relationship with 'normal' people and that for the able-bodied normal world, disabled people represent many of the things people most fear- such as "tragedy', loss', the dark and the unknown" (Hunt 1966, 155). Paul Hunt's ideas provided the basis for the early social model of disability. He and other disabled activists in Britain - many of them who were living in special institutions - set up new political (pressure) groups that were rejecting 'residential care' and the control over their lives that was hold by non-disabled experts.[11] The Union of the Physically Impaired Against Segregation (UPIAS) certainly can be described as one of the most influential political groups of that time. With the influence of Paul Hunt and Vic Finkelstein, another disabled activist who had moved to Britain after being banished from South Africa because of his

[11] The close connection between activism and scholarship has been described as a strength of disability studies (Corker and Shakespeare 2002, 13).

involvement in the anti-apartheid protest movement, UPIAS shaped the first definition of the social model in 1976:

> "In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation, in every area of life, such as education, work, mobility, housing" (The Union of the Physically Impaired Against Segregation 1976, 3–4).

Scholars outlined that the kinds of disabling restrictions and social barriers disabled people experience vary from society to society and from age to age (Oliver and Barnes 2012; Oliver 1990). Adopting a Marxist materialist approach to history, they further argued that the oppression of disabled people can be traced back to the origins of Western industrial society and the social relations of production in a capitalist society (Abberley 1987; Oliver and Barnes 2012; Finkelstein 1980). Drawing from a Marxist economic perspective Oliver claimed that individuals with impairments have always been present as part of larger social groups such as families, clans or communities. However with the emergence of capitalism and its core ideology of 'individualism', the individual became isolated and independent (Oliver 1990). The disappearance of large family units in the Western world caused the circumstance that families were no longer able to provide the necessary support for disabled and older family members (Oliver and Barnes 2012, 38). Furthermore, as the 'mode of production' changed during industrialisation, many disabled people found themselves excluded from mainstream work (Oliver and Barnes 2012). Similarly, Abberley claims that the restrictions of impairment in the capitalist mode of production form a materialist basis for a theory of disability as oppression[12]. He outlines the socioeconomic origins of

[12] Abberley outlines that also other forms of oppression such as racial and/or sexual inform the theory of "disability as oppression" as different forms of oppression are often interrelated. However there is no monolithic theory of oppression, into which you can fit black people, women disabled people, or gay people. Oppression is always specific and depends on location, content and form (Abberley 1987, 7).

impairment by showing that, in many cases, impairment is not an unavoidable 'fact of nature', but a social product, a consequence of social and political factors, such as malnutrition, lack of health care or socio-economic factors (Abberley 1992, 12–13). Furthermore, he claims that the present social order, based on capitalist values, benefits from the ongoing oppression and social exclusion of disabled people. The rehabilitation system, for example, is built on and is fed by the continuing need to restore the individual workability of disabled people who are perceived as unproductive (Abberley 1987, 9–13).

At the heart of the British social model lies the firm distinction between impairment and disability [13]. *Impairment* is defined in biological terms, and encompasses the functional limitations of bodies and minds. *Disability* in contrast is defined as a social creation, involving disabling barriers, negative attitudes and the social oppression of disabled people. Disability is redefined as something that affects an individual from the outside: while somebody may have an impairment, the disability they experience stems not from individual limitations but from the failure of society to provide the supports and to remove the barriers which prevent people with impairments from leading full lives (Swain et al. 1998; K. Johnson 2009). Probably the most prominent example for such a barrier is the build environment that is not accessible to wheelchair users due to the existence of stairs and the lack of ramps. However, the lack of signs in Braille and/or the lack of publications in simple language are also social barriers. According to the social model, such restrictions are imposed by a society which discriminates against people with disabilities and denies them the means to exercise their capabilities on an equal level with their non-disabled peers. By turning the attention to the environment, the social model makes an implicit political argument for social change (Bickenbach et al. 1999, 1176; Oliver and Barnes 2012).

[13] Initially, the social model focused on those with physical impairments: The 'P' in UPIAS stands for *Physically* Impaired, Finkelstein deals in his monograph "Attitudes and Disabled People" with the experience of wheelchair users, a group to whom he belongs. The strong focus on physical disabilities is still predominant today and has been subject to criticism. However, the social model has subsequently extended to incorporate all types of impairments: physical, sensory and cognitive (Barnes 2012, 14).

Although the socio-political understanding of disability increased the political power of disabled people and changed the self-perception of many disabled people (Crow 1992), the social model has been subject to widespread criticism. On the one hand, it has been critiqued due to its neglect of individual experiences, its strong disability/impairment dualism and the underestimation of impairment effects (Shakespeare 2006; Newell 2006; Tremain 2006; Barnes 1996; Nicholas Watson and Shakespeare 2001). On the other hand, in particular scholars working from a feminist perspective have argued that the social model ignores or underestimates the role that cultural practices and processes play in shaping disablism (Tremain 2006; Morris 1991; Watson 2003; Crow 1992). Considering the impairment/disability dualism, celebrated by its founders as the strength of the social model (Barnes 2012; Barnes and Mercer 2004; Oliver and Barnes 2012), an increasing amount of scholars claim that disability cannot be seen as merely socially constructed (Shakespeare 2006; Newell 2006; Tremain 2006; Barnes 1996; Watson and Shakespeare 2001). Referring to feminist writers such as Jenny Morris, Liz Crow and Carol Thomas, Shakespeare argues that the social model undervalues the personal experience of pain and embodied limitations that result from impairment (Shakespeare 2006, 29–53). The disability/impairment dualism and the strong focus on disability within the social model pretends that impairment is 'irrelevant', 'neutral' and/or 'positive' and does not determine the individual experiences (Crow 1992; Swain et al. 1998). In contrast to other forms of discrimination, such as racism or sexism, disabled people experience on top of the externally imposed social discrimination the intrinsic limitations of their impairment (Shakespeare 2006, 41). While agreeing with the basic tenets of the social model, Sally French, in line with other (feminist) writers (e.g. Crow 1992; Morris 2001; Thomas 1999) argue that certain impairments, such as pain, depression or vertigo are "difficult, if not impossible, to solve by social manipulation" (French 1998, 17) [14], and that they

[14] In her book "Female Forms: experiencing and understanding disability" Carol Thomas (1999) introduces the concept of 'impairment effects': It seemed to her that such a concept was required to acknowledge that impairments do have direct and restricting impacts on people's social lives – 'restricting' as judged against socially defined age-norms. "Such restrictions are, of course, to be distinguished from the restrictions, exclusions and disadvantages that people with impairments experience as a result of disability. In any one life, impairment effects and disability interlock in unique and complex ways. However difficult it may be to separate impairment effects and disability effects in someone's life, it is necessary to make such an analytical distinction within disability studies, but taking care not to mistake the former for the latter" (Thomas 1999).

are instead 'inextricable aspects' of impairments (Watson and Shakespeare 2001, 18). These scholars argue that the social model undermines the circumstance that no matter what kind of adoption or support is provided some disabling effects will persist, such as ongoing pain or a slower speed in fulfilling work or daily tasks. Shakespeare illustrates this by outlining the limitations of a barrier-free world: nature, for example, can only be altered in limited accounts. In addition, the removal of all barriers is often not practical and incompatible as different types of impairments require different accommodations. Instead of arguing for a universal barrier-free utopia, in which no disabling barriers exist, he calls for a response to special needs (Shakespeare 2006, 45–48). It is feared that the strong focus on disabling barriers creates an 'elite' of disabled people who can overcome their oppressed status in society by having disabling barriers addressed, while leaving the majority of disabled people behind (Crow 1992).

Reflecting on and acknowledging the shortages of the social model that builds on the strong impairment/disability dualism, critical disability theory adopts a version of the social model that is based on three principles; (1) disability is not the inevitable consequence of impairment, but a social construct; (2) disability is a complex interrelationship between an impairment, the individual response to impairment, and the social environment; (3) physical, attitudinal and institutional environments that fail to meet the needs of people who do not match the expectations of ´normalcy´ cause social disadvantages for disabled people (Hosking 2008). Such a version of the social model is also recognized as the 'biopsychosocial model" (Bickenbach et al. 1999, 1183) which has emerged on the international political agenda and which is reflected in the Convention on the Rights of Persons with Disabilities.

The new socio-political understanding of disability was fuelled by the emerging field of critical disability theory. Critical disability theory has only emerged at the beginning of the 21st century as the preferred theoretical framework for the study and analysis of disability issues (Meekosha and Shuttleworth 2009; Devlin and Pothier 2006; Hosking 2008). The York University in Toronto/Canada was the first University to offer a postgraduate research programme in Critical Disability Studies. Like the early critical thinkers of the Frankfurt School, disability activists and scholars started to reject traditional research methods which were based on paternalistic and medical

models of disability (Barnes 2003b; Mercer 2002; Oliver 1992). Critical scholars claimed that throughout the history of disability research, disabled people have been treated as objects and not as subjects in research processes (Abberley 1992; Oliver 1992; Barnes and Mercer 1997; Barnes 2003b). Outlining the historical changes of research production in social science in general and its impact on disability research in particular, Oliver argues that both the positivist and the interpretive paradigm produce *alienating research* and only emancipatory research can challenge the social relations of research production (Oliver 1992, 112). As Barnes and Mercer outline "to understand the social world, it is necessary to explore people's subjective 'definition of the situation and their attempts to navigate its inherent uncertainties and dilemmas" (Barnes and Mercer 2010, 5). Critical disability theorists are united by the claim that disabled people are undervalued and discriminated against in society, and that this cannot be changed simply through liberal or neo-liberal legislation and policy (Meekosha and Shuttleworth 2009, 65). Thus Critical disability theory provides a framework to assess neoliberal norms and values and their impact on the daily lives of disabled people. The goal of such an approach is to challenge neoliberal norms and values so that barriers are removed and disabled people can fully participate in contemporary societies (Devlin and Pothier 2006, 2; Welti 2005, 5). Rioux and Fraser outline the advantages of critical disability theory as follows:

> "A critical disability theory approach offers an important lens in unravelling the inherent complexities associated with disablement and equality. It begins with the assumption that theories of human rights and equality provide the necessary foundation for understanding the linkages between the existing legal, economic, political, and social rationales for the full inclusion of people with disabilities inherently unequal and disentitled to citizenship rights" (Rioux and Fraser 2006, 47–48).

In doing so, critical disability theory offers a politicized view and re-evaluation of explanatory paradigms used to understand the lived experience of disabled people (Devlin and Pothier 2006; Meekosha and Shuttleworth 2009). As illustrated above, the emancipatory vision of critical theory contains a conception of a "better world", an image of what the world could (or should) be (Alway 1995, 2). In the case of critical

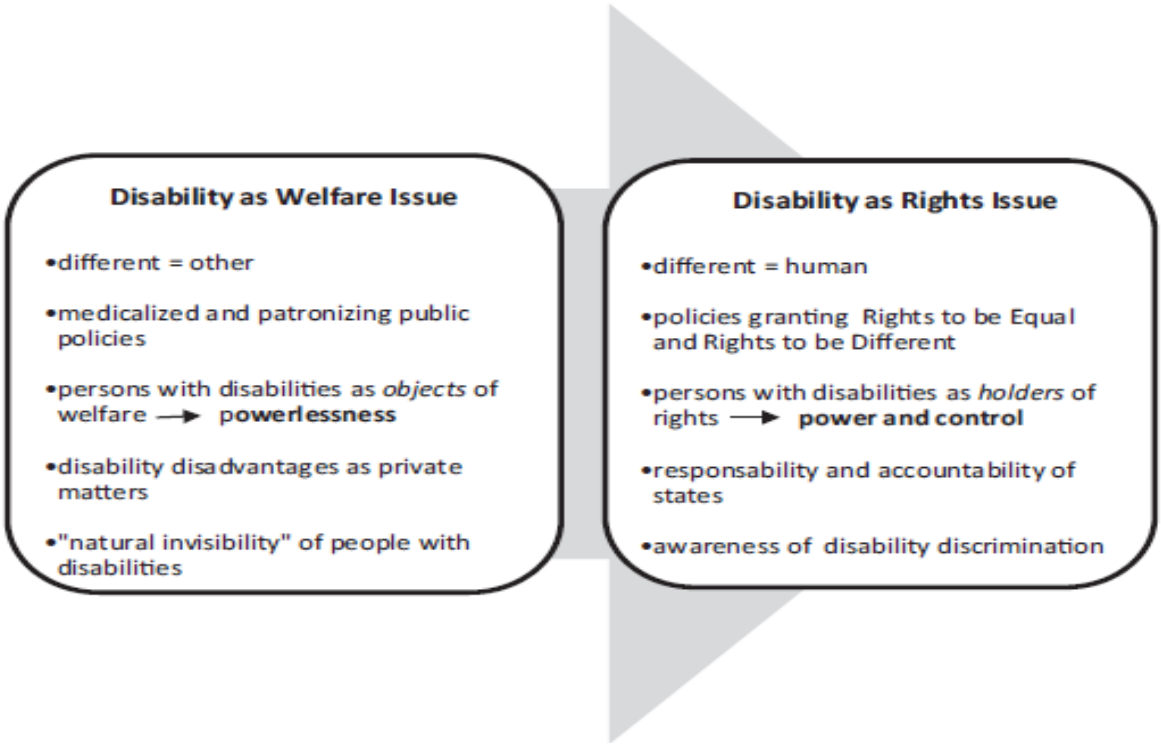
disability theory, a better world is a world in which able-bodied norms are challenged, in which systematic barriers and oppressive structures are removed and people with disabilities are fully included and recognized as part of the human diversity (Devlin and Pothier 2006; Rioux and Fraser 2006; Hosking 2008). Critical disability theory offers a suitable framework for research that puts human rights, the emancipation of disabled people and the transformation of social structures on its agenda. The impact of critical disability theory on social policy is further illustrated in the following section.

1.4 Critical disability theory and social policy

Questioning if "theory does matter?", Rioux and Fraser illustrate how divergent concepts of disability inform different policy responses to disability (Rioux and Fraser 2006). According to the authors, the main focus of policies that are underlined by the individual model or medical model of disability is the prevention, cure or elimination of disability and, whenever this is not possible, the assimilation of the disabled body and mind to ableist norms and structures. Within the medical model of disability the responsibility of the State is therefore to develop and implement laws, policies and practices that promote the segregation and the rehabilitation of disabled people (Rioux and Fraser 2006; Tremain 2006). In this traditional policy approach, rights were traded by charity (Rioux 2002).

State responsibility and, thus, policy approaches change when they are informed by a social-political understanding of disability. In such an approach, it is no longer the disabled person who has to be cured, rehabilitated or assimilated to hegemonic norms and structures, but it is the ableist structures and norms that need to change to accommodate the needs of disabled people. Consequently, policy approaches need to be transformed. The entitlement of disabled people to equal access and equal rights becomes a main policy aim. The elimination of physical barriers is only one area that is addressed in social policies that are informed by a human rights approach to disability (J. Campbell and Oliver 1996). As Rioux and Fraser further outline a genuine human rights approach to disability questions how societies are organised and structured to keep disabled people in a powerless position (Rioux and Fraser 2006, 52). The graphic below highlights the main characteristics of the human rights approach to disability in comparison to the traditional welfare approach.

Figure 1: Changing Paradigm



Source Pinto and Fiala 2015.

In the second half of the twentieth century, on both sides of the Atlantic, policy makers started to responded to emerging conceptualisations of disability and began to implement legislation that was targeting physical and environmental barriers. For instance, in 1968, the Architectural Barriers Act (ABA) was passed in the United States requiring buildings that were "designed, built, altered, or leased with federal fund" to be accessible to those with disabilities (Bruyère and Barrington 2012). In Great Britain, the Chronically Sick and Disabled Persons Act (CSDPA) passed in 1970. Although its legal effectiveness was limited, the Act was a first attempt to legally enforce access rights for disabled people in Britain (Pearson and Watson 2007). As the political consciousness among disabled people grew, disabled people and their supporters increasingly started to see themselves as subjects, as citizens who have a legal claim to equal rights and equal participation in society (J. Campbell and Oliver 1996; Barnes 2012).

Gradually too, the international agenda, and mostly as a result of the ongoing claims of disabled people and their supporters for equal social participation and equal citizenship status, several non-binding instruments emerged (see chapter 2).

Highlighting the shortages of traditional human rights bodies the demand for a disability-specific human rights convention increased in the 1990s (Quinn and Degener 2002c; Parker 2006). In 2002, Quinn and Degener evaluated the use of the United Nations human rights instruments through the lens of disability. They concluded that a disability-specific convention would combat the core problem, the 'invisibility' of disabled people in the United Nations (UN) system. Furthermore, they argued, a commitment to full civil, political and social rights for disabled people is crucial to ensure their human value as subjects and not as objects (Quinn and Degener 2002a; Abberley 1987). Similarly, Parker (2006) argues that the UN system, prior to the establishment of the UN Convention on the Rights of Persons with Disabilities (CRPD), was insufficient to protect disabled people's rights. Relying on Nancy Fraser's two concepts of justice, Parker argued that redistribution and recognition are necessary to overcome the multiple sources of the oppression disabled people experience (Parker 2006). In 2006, for the first time in history, disabled people's equal citizenship status has been acknowledged in an international legally binding instrument. Acknowledging that disabled people need special provisions to meet equal opportunities, the UN CRPD strengthens a reflexive citizenship discourse, one in which all types of rights – civil, and political, as well as economic, social and cultural – are affirmed and recognised. The empowering process embedded in the development and the creation of the international human rights agenda, the purpose of the Convention and its monitoring obligations are outlined in more detail in the following chapter.

2 Disability and human rights

The following chapter provides an overview of the international human rights framework. First, the emergence of the Convention on the Rights of Persons with Disabilities (hereafter CRPD) is outlined. It will be shown what role disabled people and their supporters played in the development and the drafting process of the Convention. Then the purpose and the monitoring obligation of the CRPD is further explored. It will be illustrated that the underlying human rights principles play an important role in particular when monitoring the Convention in practice. Therefore the second part of this chapter emphasises the human rights principles that underlie the Convention.

2.1 Emergence of the international disability human rights framework

In our contemporary time which is often described as the *'Age of Rights'* (Bobbio 1996) or the 'Human Rights Era' (Lindqvist 2004) rights are omnipresent in political and social discourses. Nevertheless, despite the ubiquity of rights, it should not be forgotten that the international human rights regime has only emerged after World War II. As Donnelly stresses human rights are a set of social values and practices and not a historical or anthropological fact (Donnelly 1999, 81). To replace the League of Nations, which has been proved as ineffective in preventing World War II, the United Nations were established on 24 October 1945. The aim was to held States morally and politically liable at the international level for the treatment of their own citizens in their own territory (Donnelly 1999; United Nations 2012a). The „civil religion“ of human rights represent a key experience of the second modernity in which human rights are no longer restricted to Nation States or national identities but in which they are perceived as universal (Beck 2001a, 45). The Universal Declaration of Human Rights (UDHR), which was adopted by the UN General Assembly on 10 December 1948 can be seen as the foundation of international human rights law. The Declaration was the first universal statement that builds on the basic principle of inalienable human rights (United Nations 2007). This first declaration inherited the so called first generation of rights, political and civil rights, and the second generation rights, social and economic

rights. Subsequently all countries have accepted the UDHR[15]. The declaration affirms that the

> "recognition of the inherent dignity and of the equal and inalienable rights of *all* members of the human family is the foundation of freedom, justice and peace in the world" (United Nations 1948, Preamble, own emphasis).

To protect vulnerable and marginalised groups such as people from different ethnic backgrounds, women, migrant workers or children, the UN body has since been implementing various group-specific human rights frameworks. The first group specific treaty was the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) which was adopted in 1965, followed by the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) in 1979, the Convention on the Rights of the Child (CRC) in 1989 and the international Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (ICMW) in 1990[16].

Disabled people, however, have remained invisible for many years in the international human rights bodies (Parker 2006; Quinn and Degener 2002a, 23–26). In the context of disability it can be critically inquired why disability is not explicitly considered in this first universal statement of human rights. Article 2 of the UDHR mentions "distinctions of any kind, such as race, colour, sex, language, religion,

[15] International human rights law lays down obligations which States are bound to respect. By becoming parties to international treaties, States assume obligations and duties under international law to respect, to protect and to fulfil human rights. The obligation to respect means that States must refrain from interfering with or curtailing the enjoyment of human rights. The obligation to protect requires States to protect individuals and groups against human rights abuses. The obligation to fulfil means that States must take positive action to facilitate the enjoyment of basic human rights.
Through ratification of international human rights treaties, Governments put into place domestic measures and legislation compatible with their treaty obligations and duties. The domestic legal system, therefore, provides the principal legal protection of human rights guaranteed under international law. Where domestic legal proceedings fail to address human rights abuses, mechanisms and procedures for individual and group complaints are available at the regional and international levels to help ensure that international human rights standards are indeed respected, implemented, and enforced at the local level. More information online available at http://www.un.org/en/universal-declaration-human-rights/ [last accessed on 25/09/2018] or http://www.un.org/en/sections/what-we-do/uphold-international-law/index.html [date of access 25/09/2018]

[16] An overview about the Core International Human Rights Instruments and their monitoring bodies can be accessed online at http://www.ohchr.org/EN/ProfessionalInterest/Pages/CoreInstruments.aspx [date of access 01/10/2017]

political or other opinion, national or social origin, property, birth or other status" (UDHR, Article 2), disability is not referred to explicitly, despite the fact that people with disabilities have been targeted and killed during Hitler's Nazi regime and many people have become disabled during the war. Furthermore, none of the equality clauses of the international bill of human rights composed of the Universal Declaration of Human Rights (1948), the Covenant on Economic, Social and Cultural Rights (1966) and the Covenant on Civil and Political Rights (1966) mentions persons with disabilities as protected group explicitly (Kayess and French 2008, 12). Up until recently, the World Health Organisation (WHO) was responsible for disability policy at international level, but reflecting its medical orientation it was concerned mainly with three topics: the definition of disability, then prevention of disability and rehabilitation measures (Degener 2009, 201).

Nevertheless, influenced by the changing conceptualisation of disability and the emerging disability rights movement, the widespread exclusion of disabled people increasingly became a topic for the international human rights bodies. Disabled individuals were increasingly beginning to frame their exclusion from society as a human rights issue (J. Campbell and Oliver 1996, 62). The United Nations Declaration on the Rights of Disabled Persons[17] in 1975 was the first international document which called for equal civil and political rights of people with disabilities. Although, the Declaration was - from a contemporary point of view - in many aspects insufficient, the document provided an initial global framework for drafting national laws and policies and played a key role in advancing the recognition of disability as a human rights issue (Rioux and Fraser 2006, 58–60). Following this first international document, the UN announced the year 1981 as the 'International Year of Disabled Persons' to raise further worldwide attention about disability discrimination. The World Programme of Action Concerning Disabled Persons in 1982 was the guiding instrument for the United Nations Decade of Disabled Persons 1982-1993. Whereas the first two objectives of the World Programme, "Prevention" and "Rehabilitation", reflected a more traditional approach to disability, the third goal, "Equalisation of Opportunities", set the path for

[17] Whereas a Convention is a legally binding treaty, which comes into force upon ratification by a certain number of States, a Declaration is not legally binding but carries moral weight because it is adopted by the international community.

changes at the international level (Quinn and Degener 2002a). The World Programme of Action stimulated new forms of cooperation, increased the visibility of disability and established a basis for a new understanding of disability. Eventually, the 1990s can be described as a banner decade for disability law as more than twenty nations enacted disability discrimination laws during this period, inaugurated with the passage of the Americans with Disabilities Act in 1990. The status of persons with disabilities shifted in many aspects; people with disabilities were no longer perceived as objects of welfare and charity but as subjects and holders of rights and responsibilities (Quinn and Degener 2002a). In 1994, following the UN Decade of Disabled Persons, the UN General Assembly adopted the Standard Rules on the Equalisation of Opportunities for People with Disabilities. The document comprises twenty-two rules which facilitate the full participation and equality of persons with disabilities. The rules cover different aspects including awareness-raising, medical and support services, education, employment, leisure and cultural activities. In the same year, the Committee on Economic, Social and Cultural Rights issued General Comment 5, clarifying how to interpret and implement the CESCR with respect to persons with disabilities.

As the first human rights treaty of the twenty-first century, the Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol (CRPD Optional Protocol) have been adopted by the United Nations General Assembly on 13 December 2006 (Parker 2006; United Nations 2007; World Health Organization 2011), marking a major shift in the way the international community treats its 650 million people with disabilities (Kayess and French 2008, 3–4). An Ad Hoc Committee of the General Assembly created the treaty during eight sessions from 2002 to 2006, making it the fastest negotiated human rights treaty in the history of the UN. The Convention was negotiated in an “open and transparent process” in which interested parties including disabled persons, their families, and the representative organisations participated (O´Reilly 2007, 58). The motto “Nothing about us without us” that marked the disability rights movement was trully enforced in the formation process of the CRPD (Sabatello and Schulze 2014; Degener 2009). As Sabatello and Schulze outline the participation of disabled people and their representatives in the negotiation and drafting process - the “New Diplomacy” - had major impacts:

> "For one, persons with disabilities were made visible. Second, voices "from within" were in fact taking over places of power of those "from outside", shifting the dynamics of the negotiations. Indeed, this close collaboration between civil society and states' delegates led some to believe that without the consent of the disability community, the Convention would not have been adopted" (Sabatello and Schulze 2014, 8).

Celebrated as an international milestone in advancing and developing the recognition of disability as a human rights issue, the CRPD is the most unmistakable international recognition of persons with disabilities' full humanity and, given its international acceptance, it has become the blueprint for the development of disability policy around the globe. Whereas the Convention does not implement any new rights, it clarifies the obligations states have to identify and adapt discriminatory and oppressive social structures that restrict persons with disabilities to fully enjoy all human rights and fundamental freedoms as defined in the International Bill of Human Rights. The Convention builds upon, and works in synergy with the previous human rights instruments addressing the matter of persons with disabilities. The following section outlines the purpose of the Convention in more detail.

2.1.1 Purpose of the Convention

The CRPD requires signatory countries to establish a mechanism to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity (CRPD, Article 1). As Don Mac Kay, a member of the Ad Hoc Committee outlined:

> "Attitudes need to change in society and in governments. Our world needs to better accommodate diversity, and our societies need to be much more inclusive and accessible. Persons with disabilities need to be more empowered. This is what the Convention seeks to achieve, but ultimately its effective implementation will be the key" (cited in (Sabatello and Schulze 2014, xiii))

Being the first legally-binding instrument on disability, the CRPD provides a "fresh impetus and imperative to governments to modify or abolish existing laws, regulations,

customs and practices that discriminate against persons with disabilities and to adopt appropriate legislation and other measures for the implementation of the rights contained in the Convention" (O´Reilly 2007, 119). In doing so the Convention lends new urgency to the task of understanding the relationship between people with disabilities and human rights (Rioux, Basser, and Jones 2011, 2). Marking a paradigm shift in the way disability is understood in policy discourses, the CRPD frames disability as an *evolving concept*, which acknowledges that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others (CRPD, Preamble, (e)). The Convention is seen as a drive for inclusion (Degener 2009) and promotes a 'diversity-approach' to disability that acknowledges disability as part of the human condition and society (Bielefeldt 2009, 6). The Convention has the task to ensure that the world's largest minority group whose rights have often been systematically and persistently violated (Mégret 2008, 495) and who remain amongst the most marginalised in many societies (United Nations 2007; Meekosha and Dowse 1997, 51) enjoys the same rights and opportunities as everyone else (Kayess and French 2008, 4). The treaty addresses the many areas where persons with disabilities have been discriminated against including access to justice; participation in political and public life; education; work and employment; freedom from torture, exploitation and violence, as well as freedom of movement. Furthermore, the Optional Protocol to the Convention provides an independent complaint and inquiry procedure for citizens of State Parties who have alleged violations of their rights, and who have exhausted national remedies (United Nations 2007, iii). States Parties to the Convention can decide if they merely sign the Convention or both documents - the Convention and the Optional Protocol. Since the CRPD has come into force, a large number of countries have signed and ratified the Convention[18]. In doing so, the State parties have demonstrated their commitment to respect the rights of persons with disabilities (Kayess and French 2008, 2). The implementation of the CRPD has been seen as an

[18] The Convention has been ratified by 177and signed by 161 countries (August 2018). Latest figures of are provided online at https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html [date of access: 25/09/2018].

“agenda for change" (World Health Organization 2011, 268; Lindqvist 2004). The monitoring obligation plays a significant role in this perception.

2.1.2 Monitoring obligation of the Convention

> “The state becomes necessary as a sanctioning, organizing, and executive power because rights must be enforced, because the legal community has need of both a collective self-maintenance and an organized judiciary” (Habermas 1996, 134).

Article 33 of the Convention on the Rights of Persons with Disabilities determines that State Parties, in accordance with their system of organisation, designate one or more focal points. Signatory States must also - in accordance with their legal and administrative systems - maintain, strengthen, designate or establish within the State Party, a framework to promote, protect and monitor the implementation of the Convention (Article 33 CRPD). With the formulation, the CRPD is the first human rights framework following the 1993 Vienna Declaration and Programme of Action that not only sought to increase the national application of human rights but also puts an emphasis on the importance of establishing national human rights institutions (Schulze 2014, 209).

As Pinto claims human rights monitoring is the activity that enables societies to evaluate whether progress in securing rights has taken place and it provides information about existing gaps (Pinto 2011b). Furthermore the monitoring process is an important instrument to enhance public awareness and empower people affected by human rights violations. Monitoring in this sense is intended to bring about social change and the critical goal of disability rights monitoring is to contribute to the improvement of the human rights protection of disabled people (Pinto 2011b, 455–56).

Article 34 of the CRPD further outlines the framework for a Committee on the Rights of Persons with Disabilities (hereafter referred to as “the Committee”). The members of the Committee[19] shall be elected by State Parties. The State Parties have

[19] An updated list of elected Members of the Committee, their nationality and the date of terms when the mandate expires can be found online at www. ohchr.org/EN/HRBodies/CRPD/Pages/Membership.aspx [date of access: 03/06/2018].

the obligation to submit national reports to the Committee. The reports shall outline what measures States have taken to give effect to its obligations under the CRPD (Article 35)[20]. The Committee has the task to review the periodic reports of the State Parties. After considering the reports, the Committee makes suggestions and general recommendations and if necessary request further information from the State Parties (Article 36). In addition to the official country reports, alternative reports - often called shadow reports - of concerned civil society entities have enriched the reporting system. These reports present a different perspective on the *de facto* situation than the official country reports and have been welcomed by the UN expert committees as a form of additional information (Lindqvist 2015, 14). As Lindqvist sums up

> "it is the monitoring of the situation that makes the difference. The CRPD is pioneering more effective ways to allow affected individual and groups to speak for themselves" (Lindqvist 2015, 22).

In both countries which are subject of the present research, the first monitoring cycle has been completed. Portugal and Germany have both issued the first country reports and have replied to the List of Issues that the Committee on the Rights of Persons with Disabilities has been issued. In Germany the next country report is due in March 2019 (see chapter 5) and in Portugal the next country report is due in November 2022 (see chapter 6).

Rioux, Basser and Jones (2011) provide in their volume "Critical Perspectives on Human Rights and Disability Law" tools with which to critically assess the exercise of law itself, using the human rights principles enshrined in Article 3 of the Convention as an underlying framework. They argue that the underlying principles shed light on what is needed to give effect to the human rights of people with disabilities (Rioux, Basser, and Jones 2011, 3). They further conclude that

> "the success of the CRPD, and of law generally, will be measured by the extent to which the underlying principles are reflected in the development and

[20] The first report is due two years after the entry into force of the present Convention and thereafter subsequent reports are due at least every four years or on requests of the Committee (Article 35, para. 1 and 2).

administration of laws, policies and programmes, in the rulings of domestic courts and tribunals and in the changes experienced at the grass roots" (Rioux, Basser, and Jones 2011, 487).

To adopt a critical human rights approach in the monitoring process it is therefore necessary to be familiar with the underlying human rights principles of the Convention.

2.2 Human rights principles in the Convention

As outlined above, the underlying human rights principles play an important role in the monitoring process as they serve as indicators to show not only *if*, but to what extent and in which *qualitative manner,* human rights have been implemented into legal decision-making and effective practice. The following section reflects on the underlying principles of the CRPD through the lens of disability. Prior to the implementation of the CRPD, Quinn and Degener outlined that four values in particular, namely *dignity*, *autonomy*, *equality* and *solidarity*, are of importance to underpin a system of basic freedoms for people with disabilities (Quinn and Degener 2002a, 24). Building on Article 3 of the CRPD "General principles" the present analysis focuses on the following five principles: (1) Dignity, (2) Autonomy, (3) Inclusion, Participation & Accessibility, (4) Equality and Non-Discrimination and (5) Respect for Difference.

2.2.1 Dignity

"Recognition of the inherent *dignity* and of the equal and inalienable rights of *all* members of the human family is the foundation of freedom, justice and peace in the world" (United Nations 2012a, Preamble, own emphasis).

The English term "dignity" stems from the Latin word "dignitas" which is defined as "being worth". In contrast to the contemporary understanding, in which the value of dignity is generally attributed to all members of the species *homo sapiens*, historically, only people belonging to elite groups have been ascribed with human dignity (Donnelly 2013, 29, 121–26). The Roman conception *dignitas* referred to what is most excellent and worthy of respect, attributes which were only found in the best humans

(Donnelly 2013, 123). In this way, dignity functioned as a principle of hierarchy and served to determine social relationships (Donnelly 1999; Basser 2011).

In line with previous human rights declarations, the CRPD stresses the importance of human dignity as a foundational concept - it is the "anchor norm of human rights" (Quinn and Degener 2002a, 14). Article 1 of the CRPD in which the purpose of the Convention is outlined, also highlights the importance of dignity:

> "The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent *dignity*" (United Nations 2006, Articel 1, own emphasis).

The treaty itself, as well as previous human rights instruments, offers no clear definition of the exact meaning of human dignity or why the rights enshrined are grounded on human dignity (Donnelly 1999). Despite this shortage, Donnelly further claims that Kant's philosophy has had an influential impact on contemporary human rights legislation and the modern conception of dignity (Donnelly 2013, 128–32). For Kant dignity is tied up with morality and inherits a quality of the intrinsic human worth as in contrast to a material price. In Kant's account of human dignity, people need to be seen as an end in themselves rather than means to an end (Thilly 1918, 650; Donnelly 2013, 127). In line with Kant's thinking Basser argues that:

> "the attribution of dignity is not dependent on social status, political affiliation, economic value, religion, ethnicity, race, genetic make-up, the ability to reason, physical or mental ability or merit. […] Each human being is deemed to be of inestimable value because of his or her inherent value of the human person" (Basser 2011, 20).

Quinn and Degener, in turn, state that

> "each individual is deemed to be of inestimable value and nobody is insignificant. People are to be valued not just because they are economically or otherwise useful but because of their inherent self-worth" (Quinn and Degener 2002a, 14).

The entitlement to human rights through the CRPD provides a claim for the inherent dignity of disabled people. In doing so their equal worth is valued and a tool for empowerment is provided (Rioux 2002; Basser 2011, 18). From a disability perspective, one problematic aspect of the historical conception of dignity is the circumstance that dignity has often been tied with the ascription of autonomy and the ability for practical reason (Basser 2011, 26). Throughout history, disabled people have been denied human dignity on the basis that their 'limitations' and deficits mark them as quasi-humans. Even nowadays, there is still a social impulse to rank people in terms of their social and economic usefulness which is contrary to a human rights perspective (Quinn and Degener 2002a, 14). Welti outlines that a denial or downgrading of specific human rights based on individual productivity and intellectual abilities cannot be the achievement of a free discourse. The claim for human rights inherits a minimum of reciprocity of the human being as legal person within a state and an acknowledgment that human beings are connected with each other through social relations. Human beings need to be aware of the fact that everyone can become disabled at any stage throughout the life circle. The ability to put oneself in the situation of the other is, therefore, a basic prerequisite to accept human dignity as an underlying principle for human rights (Welti 2005, 384–93). A human rights approach which claims that dignity is a central element, cannot be dependent on the ability of the person to act rationally or to act independently of all others (Basser 2011, 26).

Focusing specifically on dignity at work, Randy Hodson (2001) identified four challenges; namely (1) management abuse, (2) overwork, (3) limits on autonomy, and (4) lack of employee involvement. He claimed that social relationships at work are a component of a job with dignity and that "life demands dignity and meaningful work is essential for dignity" (Hodson 2001, 3). Researchers have also drawn a direct link between the emergence of manufacturing work and the decline of dignity at work. The monotone work that comes along with the industrialization and the division of labour processes often leads to undignified work conditions (Brock 1969; Pietsch 1952). Reflecting on Hodson´s work, Vicki Smith frames a good job that confers dignity as a job "that pays a living wage and provides benefits; enables workers to exercise their voice inside their workplace and earn respect from co-workers" (Smith 2016, 40). She

further analyses that the fear about the future and cynicism about their long-term prospects continually eat away workers sense of dignity. On the contrary, employers who support a work environment in which employees feel cared about and invested in strengthen the sense of dignity among their employees (Smith 2016, 50).

2.2.2 Autonomy

> "Autonomy as a value associated with dignity derives from the ancient Greek commitment to autonomy or self-governance. It entails opening up a free or uncoerced space for voluntary action based on a person's conscience and freely made life choices, while preserving comparable liberty for others" (Rioux 2002, 15).

The concepts of personal freedom and autonomy have influenced the entire history of human rights - in particular the history of civil and political rights (Donnelly 1999). As Elias (1991) and others (Ishay 2004; Donnelly 1999) point out the concept of the autonomous, reasonable individual being has been promoted since the emergence of natural rights in the Enlightenment era and has been strengthened since the rise of capitalist societies (Elias 1991, 76). Back then, the concept of natural rights and individual autonomy were found to be a powerful argument against aristocratic and feudal privileges (Ishay 2004, 64). Honneth argues that even nowadays, the claims for justice can only be legitimised by respecting individual autonomy (Honneth 2011, 38).

Considering the historical, longstanding and still ongoing restriction to disabled people´s autonomy all over the world, the strong emphasis on autonomy for persons with disabilities within the disability rights agenda is remarkable. The achievement of autonomy for persons with disability is a primary goal of the Convention. This is shown in article 3 of the CRPD which outlines that the first general principle shall be "respect for inherent dignity, *individual autonomy* including the freedom to make one's own choices, and independence of persons" (Article 3, CRPD, own emphasis). Referring to the strong focus on autonomy within the disability rights framework, scholars have even questioned why the Convention does not mention a "right to autonomy" as such (Mégret 2008, 512). The strong emphasis on autonomy marks a turning point in disability policy and legislation. Throughout history disabled people, in particular people with mental and intellectual disabilities, have been denied autonomy and self-

determination, as they have been perceived as non-rational human beings (Finkelstein 1981; Shakespeare 2006; Oliver 1990; Waldschmidt 2003). This restriction on disabled people´s autonomy is based on enlightenment philosophy in which humans are perceived as reasonable beings and "morally free" persons who make decisions based on standards of rationality (see Kant´s Categorical Imperative)[21]. The capacity of self-directed action and behaviour is a presumption to the value of autonomy (Quinn and Degener 2002a, 15). If a person is (mentally) disabled or sick, the social and legal judgement is made that there is a lack of rational thinking, and thus a lack of capacity for moral freedom. Based on this assumption, a restriction to one's own autonomy is deemed as necessary, in particular if a person depends on the support of others (Shakespeare 2000; Waldschmidt 2003).

The lack of opportunities and choices of disabled people, further limits their autonomy or self-determination (Welti 2005, 497). For example, if work-places are not accessible for wheelchair users, their choices are more likely restricted to those work-places that are accessible. Welti outlines that for many disabled people a prerequisite to autonomy is the fulfilment of basic human needs (Welti 2005, 499). In other words, if basic human needs are not met - such as personal care or education - access to employment is constrained. In regards to basic human needs and disabled people, Charlton shows yet another obstacle, closely linked to the restriction of disabled people´s autonomy and control:

> "To recognize necessity requires an understanding of society, but to understand society you must engage it, act on it, change it, and at some point have some control of it. Most people do not have enough control of their lives. Without control, people cannot master necessity or at least key aspects of it" (Charlton 2000, 160).

The lack of control and the lack of community based support services for disabled people leads to the involuntary placement and segregation of disabled people all over the world. In the 1970 -in response to this violation - several American Universities

[21] John Locke (1632-1704) established a list of basic natural rights which understood that all men are by nature free, equal and independent (Locke 1690, cited in (Hayden 2001, 72–79)). Locke contends that all human actions are controlled by natural law, defined by the manifestation of human reason.

developed self-help programmes to enable disabled students to attend mainstream courses. These later evolved into what became known as 'Centres for Independent Living' (CILs) (Barnes 2003b, 3). The first Centre for Independent Living (CIL) was established at the University of California, Berkeley (Mason 1990; Jolly n.d.). The growing demand of disabled activists and their supporters for more control over their lives, including real accommodation choices in the community, increased the number of user-led services and self-help group in various countries (Finkelstein 1981). In many countries Centres for Independent Living emerged that where run, controlled and organised by disabled people and aimed to support the struggle for choice and control over the required assistance. The CILs offer peer support, services and training to disabled people and their families (Jolly n.d.; Barnes 2006). In broad terms, independent living means living by one's own rules and making own choices about all aspects of life. For many disabled people, independent living means a "late liberation" (Waldschmidt 2003). In contrast to traditional support systems - which are according to Finkelstein (1981) run and maintained by "able-bodied chauvinists and segregationists" – the independent living model puts the disabled persons in charge - s/he becomes the boss (Jolly n.d.; Shakespeare 2000). In this context, autonomy is associated with the capacity to "self-government", to live one´s life according to one´s plans (Ben-Ishai 2008, 3).

Contrary to the common liberal conception of independence, disabled activists stress that independent living is not about doing things on their own *without* assistance, but having the possibility to employ others that provide the necessary assistance needed to fulfil daily tasks, such as getting dressed or lifting in and out of bed. On the core of the independent living concept lies the distinction between physical and social dependency (Shakespeare 2000, 63). Within independent living models, the power relations are shifted, away from professionals to the disabled people themselves. This circumstance creates resistance amongst traditional service providers and charities. Therefore, it is no surprise, that in in many countries, independent living, personal assistance and direct payment schemes are still an exception, limited to a particular age group or not available at all[22] (Jolly n.d.;

[22] In Germany, the concept of personal assistance (the so called 'employer model') as well as an

Shakespeare 2000). The literature further shows that where independent living options and direct payments schemes exist they are often not a real option as the levels of resources are insufficient (Barnes 2006). An early empirical study in the UK shows that having sufficient money to pay for personal assistance is the key factor in giving disabled people the same choices as non-disabled people take for granted (Morris 1993, 170). As Morris points out 'choice and control' are essential in order to achieve self-determination. Self-determination in turn is a crucial part of social citizenship (Morris 2005, 21).

Outlining the limitations of the independent living model, Shakespeare (2000) interrogates the implications that other theoretical and practical approaches might have that condemn traditional (paternalistic) notions of care and dependence. Shakespeare outlines that the independent living/personal assistance model that has been developed in particular for people with physical impairments requires modifications when applied to other impairments (see also Finkelstein 1981). Referring to feminist scholars, Shakespeare explores the financial, political and practical limitations of the independent living model (Shakespeare 2000, 68–69). Feminist writers, such as Sally French and Jenny Morris propose an alternative theoretical model of care that aims to deconstruct the notions of independence itself (Shakespeare 2000). In her paper 'What's so great about independence' Sally French outlines that the pressure to become independent can also be seen as a form of oppression, as disabled people are pressured to 'manage' and 'overcome' their disability, to be 'normal' and 'independent'. She further shows that "striving for independence in terms of basic practicalities when, for that person, there are better

infrastructure to support independent living has been established. However, whereas the Federal Participation Law (Bundesteilhabegesetz) promotes free choice of living arrangements and the transition from institutional care to private households, it inherits at the same time the so called 'higher cost reservation' (Mehrkostenvorbehalt). This reservation determines that people with disabilities can be forced to live in residential homes and/or forced to pool benefits/assistance if private and individual solutions are more expensive and/or considered unreasonable.
In Portugal, the majority of disabled people live with their families, as the family is expected to provide for the well-being of their members. In 2015, the first and so far the only project that promotes independent living was launched in Lisbon. The project was funded by the Lisbon city hall and lasted until the end of 2017. Five participants with a physical disability were supported in the pilot project. In 2017 a new pilot project was launched that promotes independent living through personal assistance from 2017-2020. The projects aims to create independent living centres (CAVIs) run by disability organisations providing personal assistance to people with disabilities.
For further information see http://www.disability-europe.net/dotcom [date of access 19/10/2017]

things to do can seriously reduce independence by restricting the disabled person's freedom of thought and action" (French 1998, 46). Within the feminist ethic approach to independence, dependence on others is seen as a core concept of human nature (Waldschmidt 2003; Morris 1997; French 1998) and the notion of mutual *interdependence*[23] is promoted instead. In the context of disability a more reflexive and critical interrogation into the concept of autonomy and its normative cultural and socio-political meaning is required (Waldschmidt 2003; Morris 1997). By strengthening a concept of autonomy that includes mutual interdependence, the inclusion and participation of all human beings in society can be achieved.

2.2.3. Inclusion, participation & accessibility

The previous section has shown that as a response to the lack of control and the segregation of disabled people in residential homes, the independent living movement emerged in the 1970s. The movement emphasised self-determination and equal citizenship status and advocated for people with disabilities to obtain full social and physical inclusion in their communities. Nevertheless, disabled people's capacity to participate in society remains to date restricted by legal, social and physical barriers that result from institutional design and/or the lack of support provided by the state and community to those with disabilities (Rioux 2002; Kitchin 1998). To achieve the principle of inclusion, the prevention and removal of physical, attitudinal, social and organisational barriers is a prerequisite (Jones 2011). Accessibility is one key aspect of an inclusive society. Thus article 9 of the UN CRPD provides a framework for the principle of accessibility. The Article outlines that

> "States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas" (Article 9, UN CRPD).

[23] Martha L. Edwards shows that the modern notion of independence was unknown in the ancient Greek world and interdependence of an individual within his/her family and community was the normal state (Edwards 2000).

Physical barriers, such as inaccessible public transportation, are the most obvious restriction to full participation. However, spatial exclusion is only one aspect of the exclusion that disabled people face in our societies. Discriminatory attitudes and paternalistic worldviews in which disabled people are perceived as inferior also facilitate social exclusion. Fandrey and others (e.g. Stiker 2002; Edwards 2000) show that the social status of disabled people and thus their ability to participate in society has changed throughout history. In the middle age, malformations and disability were natural and prominent in everyday life (Fandrey 1990; Stiker 2002). As normality was a "hodgepodge" the segregation of disabled was no concern[24] (Stiker 2002, 65). For many disabled people begging was the only mean to sustain an income. As a division into the private and public sphere had not developed yet, the family was the only social entity which was responsible for the wellbeing of disabled family members – consequently care was provided within the family. In contrast to today's perception, begging and hence begging disabled people were socially accepted within the feudal system of medieval Europe. There was an overall belief that the poor are closer to god and therefore supporting beggars was considered as a mean to become closer to god (Fandrey 1990, 29). In the 18th century, the Enlightenment process influenced the social status of disabled people. A more and more secular world-view became predominant and ill health was no longer considered as given by god. During this time period, attitudes towards people with disabilities changed and begging became socially "ostracized". Subsequently disabled people lost their social acceptance. Charity was established as a mean of control (Stiker 2002, 73) and disabled people were largely segregated in poor or workhouses. Until the 19th century disabled people were generally included in mainstream workhouses and hospitals or cared for in the private sphere by their families.

Only in the 19th century, the first disability-specific institutions emerged. In Germany, for example, the first special institutions for physical disabled people ("Krüppelanstalten"), was founded in 1832 ("Technische Industrieanstalt für krüppelhafte Kinder" in Munich). The main aim of this institution was to train physical disabled children to become factory workers (Fandrey 1990, 143). In the Western

[24] In that time, people with a severe disability seldom reached adulthood.

world two World Wars contributed to the high rise of impaired people. As a consequence, social policies and measures were introduced that aimed to heal the disabled body and mind and assimilate it to the norm. As Stiker outlines the 20th century marked the *birth of rehabilitation* (Stiker 2002, 121). The rehabilitation paradigm further increased the segregation and exclusion of disabled people from the wider society (Stichweh 2010).

Stichweh claims that the sociology of inclusion and exclusion is based on membership and solidarity in the way Durkheim framed it: Exclusion is the disruption of the social solidarity. If we understand social interrelations based on the roles every person has been ascribed due to his or her social status, a person who is excluded is no longer expected to fulfil certain social roles (Stichweh 2009). In other words, spatial exclusion comes along with the exclusion from social expectation. For example, a person who is segregated in institutional care is no longer expected to sustain an income through work but is entitled to social care and benefits. Kitchin stresses that "the organisation and writing of space are expressions of disablist power relations within society. The spatialities of disability are configured to convince disabled people that they are `out of place' (Kitchin 1998, 354). Similarly Quinn & Degener argue that:

> "the social construct of disability is used not only to set people apart but also to keep people apart. All points of access to the structures of everyday life – the world of education, of work, of the family or of social interaction – are established largely by reference to the dominant norm, in this instance that of the able-bodied. As deviations or differences from the arbitrarily selected norm are generally not catered for, difference serves as a ground for subtle (and sometimes not so subtle) exclusion. For example, the built environment is constructed for those who can walk and not for those who use wheelchairs. The communications environment generally assumes a capacity to listen and to speak. The education environment makes little allowance for different ways of learning and so on" (Quinn and Degener 2002a, 15).

The aim of the CRPD is to tackle these longstanding social practices by condemning exclusionary social institutions and promoting the inclusion of disability in mainstream

policies and measures. Some disability theorists outline the shortcomings of this approach: In her work, Reeve shows the provision of “reasonable adjustments” or “reasonable accommodations”[25] that guarantee an inclusive access for all – including people with diverse impairments - can create *inadequate* adjustments. Such inadequate adjustments can create psycho-emotional barriers which maintain social exclusion and isolation as they are too distressing or humiliating to use (Reeve 2013, 104). The fact that disabled toilets are often locked and that disabled people have to ask for a key before going to a public toilet is only one example that many wheelchair users experience as humiliating.

Another obstacle of the current inclusion approach is outlined by Uwe Becker who condemns the strong focus on inclusion in society without questioning the underlying social structures. He claims that without a correction of the current emphasis of economic utilisation of human capital within the inclusion debates, inclusion threatens to become a disaster for many disabled people (Becker 2015). Similar arguments are made by Paul Abberley (2002) and Ernst von Kardorff (2010) who argue that a theory of social inclusion that puts a strong focus on economic inclusion does not offer a satisfying approach for many disabled people. Becker condemns the common mainstream debates about inclusion and argues instead for a meaningful and critical debate that no longer means “inclusion” (»Einschluss«) in prevailing social structures but an acceptance of diversity to create *new social structures* (Becker 2015, 17). Arguing that inclusion relies on resources (in particular by the means of „reallocation“) and professionality and thus should not be misunderstood as a way to save money, Steinhart claims that „inclusion treads on everybody’s toes“, and, thus, an inclusive society requires a significant transformation of social practices and structures (Steinhart 2010, 67).

[25] In the UK the term "adjustments" is used instead of "accommodations". The term “reasonable accommodation” has the same meaning and is used more commonly in international legislation and in the United States, where the concept was developed and introduces in 1990 with American with Disabilities Act.

2.2.4 Equality and non-discrimination

> "Discrimination is the very negation of the principle of equality and an affront to human dignity" (Symonides 1998, 11).

Discrimination and anti-discrimination legislation are closely interrelated with the human rights agenda. The following provides a brief insight in the three heuristic models of equality before focusing on non-discrimination and inequality from a disability perspective. In current human rights and social justice discourses, three different concepts of equality are predominant (Taylor-Gooby 2012; Rioux and Riddle 2010); namely the '*equal treatment*' model also known as '*formal equality*', the '*equality of outcome model*', also known as 'substantive equality' model and the '*equal opportunity model*' (Rioux and Fraser 2006; Rioux and Riddle 2010; Quinn 1995; Quinn and Degener 2002a). The three concepts make different claims for the meaning of equality and suggest different burdens of responsibility for the government and the individual (Morris 2011, 53).

The 'formal equality' or 'juridical equality' model depends on sameness and prohibits direct discrimination. The model aims to treat all human beings equal regardless of their human characteristics such as race, gender, disability, or sexual orientation. Since unequal treatment based on such characteristics is deemed to be arbitrary, juridical or formal equality requires society to ignore differences. Within this model disabled people often find themselves in a disadvantaged position, because reasonable accommodation and accessibility is not provided (Quinn and Degener 2002b). Bickenbach outlines the contradiction:

> "in order to achieve equality, individuals or groups feel pressure to deemphasise features of themselves that mark them as different; yet, in the case of disability, ignoring the real differences created by impairments can stand in the way of practically achieving equality, since without accommodations and assistive technology, full participation in society is impossible" (Bickenbach 2012, 87).

The 'equality of outcome' or the concept of 'substantive equality' is a more expanded concept that attempts to make a real difference to people's wellbeing, ensuring that despite human differences, equal outcomes are achieved. This model

moves behind formal legalism and provides a new basis for distributive justice (Morris 2011, 54). The equality of outcome model entitles each person to certain minimum rights regardless of her/his contribution or capacity to contribute. The model also inherits the claim for redistribution of state resources and ongoing support in form of reasonable accommodation to enable people with disabilities to exercise the same rights as all other people do (Rioux and Fraser 2006, 54). However, as Quinn and Degener argue, the equality of outcome model can also perpetuate injustice, as it focuses on results rather than on treatment. In this way segregated institutions, such as special schools for disabled students could be justified on the grounds that they offer the same educational outcomes and degrees as regular schools (Quinn and Degener 2002b).

The 'equality of opportunity model' can be traced back to the ideas of Dworkin who calls for "equality of resources" (Dworkin 2000) and Rawls' "principles of justice" (Rawls 1999). Quinn and Degener outline that

> "one of the main unarticulated premises of the philosophy of "equality of opportunity", in general and in the context of disability, is that every human being has something to contribute to humanity and that social structures should be built inclusively with human empowerment as a key goal" (Quinn and Degener 2002a, 18).

Cudd argues in similar terms, when she defines equality of opportunity as a human right that no one should be categorically excluded due to his/her social status. Instead equality of opportunity requires seeing "people as individuals with preferences, resources and abilities and not as members of groups that we despise or disdain" (Cudd 2013, 207). Referring to equality of opportunities in employment, Sutherland claims that:

> "[the equality of opportunity model] would enable disabled people to start influencing the nature of our society directly, by gaining access to the roles which control its operation: Buildings would be unlikely to be inaccessible if designed by architects who were themselves wheelchair users. Children with disabilities would be less likely to let themselves be confined to a human scrapheap if they were

taught by confident and supportive adults who knew what their needs and worries were from their own experience of having the same disabilities" (Sutherland 1981, chap. 4).

In the case of disability the equality of opportunity model creates however also a dilemma, as it only grants the opportunity to access certain rights. Once the right is granted the model presumes that the natural characteristics of disabled people can somehow be overcome and that disabled people can compete with their non-disabled peers on equal terms (Rioux and Fraser 2006, 54). Despite its shortages the concept of equal opportunity is currently the most frequently applied equality concept in modern disability and anti-discrimination legislation and it is said that the equality of opportunity model is more compatible with the competitive market economy than the equality of outcome model (Quinn and Degener 2002b).

In the 1980s, disability theorists brought the issue of discrimination to the political agenda (Finkelstein 1980; Abberley 1992; Barnes 1996). Influenced by Marxist thinking, these authors introduced the idea of institutional discrimination (Oliver 1998, 260) and the concept of oppression (Barnes and Mercer 1996; Abberley 1987). Using a Marxist approach they mainly focused on the discrimination of disabled people in labour processes. Several states responded with the initial introduction of equality provisions and anti-discrimination laws that aimed to protect disabled individuals. The United States and Canada were the first countries that started to implement scattered equality provisions in different areas of law for disabled people. More comprehensive disability anti-discrimination laws followed in the 1990s. The Americans with Disabilities Act of 1990[26] is often described as a landmark law (Quinn and Degener 2002b; Bruyère and Barrington 2012). Despite the introduction of disability policy, no universal definition of disability-based discrimination exists, and no universal concept of what equalisation of opportunities for disabled persons actually entails (Quinn and Degener 2002b). In their survey on international, comparative and regional disability law reform, Quinn and Degener found, indeed, that countries took various legal

[26] Bruyère and Barrington outline that it does not seem that the ADA has increased the labour force participation and that some researchers instead argue that the ADA even had a negative impact (Bruyère and Barrington 2012).

approaches to protect persons with disabilities against discrimination, e.g. in constitutional, criminal, civil, or social law. From country to country and even within single countries, different views of equality underlined these legal approaches (Quinn and Degener 2002b). The implementation of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities aimed to change this practice. However, the non-binding instrument, which was introduced by the UN in 1993, was more a moral than a legally binding obligation to states. Although, the Standard Rules indicated principles for responsibility, action and cooperation, only the CRPD offers a legally binding definition of equality and non-discrimination. Article 5 of the CRPD "Equality and non-discrimination" states that

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention (CRPD, Article 5).

The definition of the CRPD inherits the concept of "reasonable accommodation" which was developed in the United States and first promoted in the Americans with Disabilities Act of 1990. Under the CRPD state parties are responsible to ensure that reasonable accommodation is provided. Further the denial of reasonable accommodation is considered a form of discrimination. Article 2 of the CRPD defines reasonable accommodation as:

> “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms” (CRPD, Article 2).

Number four of Article 5 of the CRPD also introduces the measures of positive discrimination or affirmative action. Affirmative action or positive discrimination is deemed necessary when the prohibition of discrimination alone is insufficient and different treatment is necessary to achieve *de facto* equality (Welti 2005, 434). In the labour market, for example, affirmative action (or positive discrimination) includes quota schemes that require an employer to hire a certain percentage of disabled people.

2.2.5 Respect for difference

Closely connected with the principle of non-discrimination and equality is the principle of ‘respect for difference’ and the promotion of diversity (International Labour Organisation 2016; I. M. Young 1990; Fraser 2008; Fraser and Honneth 2003; Honneth 1994; Squires 2006). Iris Young argues that theories of justice that reduce social justice to distributive justice assume the public as a homogeneous group. As a consequence, they fail to consider institutional arrangements for people who do not culturally identify with hegemonic white Western male norms of reason and respectability. She further urges that normative theory and public policy should undermine group-based oppression by affirming rather than suppressing social group differences (I. M. Young 1990). As outlined in chapter 1, Adorno argued that a truly emancipated society would allow "the realization of universality in the reconciliation of differences"; such a society would be one in which "people can be different without fear" (Adorno 1951, 102). Drawing parallels between current debates on human rights and the twentieth-century debates on human nature, Brown claims that the “respect for difference" and a generous tolerance produce more attractive politics than any attempt to impose one particular "form of life on all others” (Brown 2013).

The focus on diversity became fashionable in economic theory in the 1980s - in particular in organisation studies. The first diversity literature focused on people with

diverse ethnic backgrounds, nationalities, religion, age and social class (Janssens and Steyaert 2003). A main focus of the scholars was to find and analyse the effects of diversity management within organisations. Arguing that there is "clear and increasing evidence that diversity can improve the performance and competitiveness of a business" (International Labour Organisation 2016, 21) a recent International Labour Organisation (ILO) report on "Promoting diversity and inclusion through workplace adjustments" extends the "traditional" diversity categorisation by focusing in particular on four specific categories of workers, namely workers with disabilities, workers living with or affected by HIV or AIDS, pregnant workers and workers with family responsibilities and workers who hold a particular religion or belief. In line with the existing literature, the ILO report states that many standards and traditions in work procedures have been shaped by the people who historically dominated the labour market, namely male workers who were in good health and who were not constrained by caring responsibilities (International Labour Organisation 2016, 24).

Despite the international promotion to include disability in diversity approaches and debates about human nature, available research has found that people with disabilities and their differences are not valued within work processes (Parker Harris, Randall, and Fisher 2014; Woodhams and Danieli 2000) and companies invest significantly less in promoting disability equality than in promoting racial and gender equality (International Labour Organisation 2007, 85). Critical disability scholars show that ableism and the construction of an abled-bodied norm has led to the neglect of natural human characteristics, such as impairment, vulnerability, pain or dependency which are commonly associated with disability (Campbell 2009; Linton 1998; Siebers 2001; Morris 1991). Finkelstein connects the emergence of an able-bodied norm with the development of medical and biogenetical improvements:

> "Human beings are by nature, weak, vulnerable and physically imperfect. But throughout history people with capabilities have striven for perfection and the more they have managed to intervene in our body structure the more people with impairments have been marginalised.[...] Our vulnerability is seen then as a condition that separates us from what is regarded as normal. This transference of

vulnerability [...] has created a dangerous illusion about the meaning of normality" (Finkelstein 2001, 5).

Social sciences such as psychology or education have been particularly influential in creating existing deterministic narratives which conceptualise disability as 'deficit', 'deviance from the norm' or as a 'pathological condition' (Campbell 2009; Linton 1998; Davis 2006; Newell 2006). Normality is constructed in a way that creates the 'problem' of the disabled person (Davis 2006, 9). Within the abled-bodied norm the disabled body has the function to secure the performative enactment of the normal (Campbell 2009, 12). Disability scholars and advocates have argued that disability is a complex, situated, variable and contingent concept and therefore it cannot be reduced to a singular identity. Disability is instead marked by intersectionality and plural identities (Shakespeare and Watson 2001, 19). Identity discourses fail to address that many disabled people struggle with the identification as disabled:

"whilst all disabled people are keen to achieve recognition and respect, they are not all seeking to be recognised as having essentially different identities from those of non-disabled people, or as being a part of a different culture, but rather, many are seeking to be treated as equal persons" (Beckett 2005, 417).

Disability is an embodied identity, however, many disabled people don't want to see themselves as disabled, and therefore downplay the significance and impact of their impairment (Watson and Shakespeare 2001, 20; Parsons 1999). Furthermore, disability in contrast to other social categories is not a fixed status, but a dynamic one. While there is nothing inherently unpleasant about other group's embodiment, such as skin colour or sexual orientation, impairments may have negative effects on people's lives, such as pain, or a short life and hence they cause fear, as Davis outlines:

"No whites will become black; few straights will become gay; but every normal person can become disabled. All it takes is the swerve of a car, the impact of a football tackle, or the tick of the clock to make this transformation. [...] disability is the identity one may become part of but didn't want. This is the silent threat that makes folks avoid the subject, act awkwardly around people with disabilities..." (Davis 2002, 4).

As a consequence, many disabled people struggle to identify as disabled (Linton 1998) which leads to wider struggles in their fight for human rights (Charlton 2000; Parsons 1999). In her attempt to construct an ethics of care that promotes human rights, Morris focused on the term “difference” and claimed that equality relies on the acknowledgment of differences caused by impairment and the need for specific entitlements (Morris 2001). The acceptance of embodied diversity and impairment is a necessary development in disability studies, which might lead to a modification of the notion of normalcy (Siebers 2001, 749). Shakespeare and Watson promote an embodied ontology that argues that there is no qualitative difference between people with and without disabilities, because every human being has some kind of impairment. Consequently "impairment is not the core component of disability ... it is the inherent nature of humanity" (Watson and Shakespeare 2001, 24). A society, in which each member can acquire a disability at any time, has to engage proactively and acknowledge, accommodate and celebrate human differences, whatever its cause, rather than oppress it (Barnes 1996; Morris 2001). It is claimed that such an assumption will lead to the recognition that disablement and impairment is not merely the physical state of a small minority of people; rather it is the normal condition of humanity (Sutherland 1981, 18). The CRPD calls for the “acceptance of persons with disabilities as part of human diversity and humanity” (CRPD, Article 3) reassuring that the majority of people will be affected by disability at some point in the life circle.

Concluding remarks

This chapter has illustrated the development and emergence of the human rights framework, its purpose and its monitoring obligation. It has been shown that the underlying human rights principles play an important role in the monitoring process as they serve as indicators to show not only *if*, but to what extent and in which *qualitative manner* human rights have been implemented into legal decision-making and effective practice. People with disabilities have long been deprived of their most basic social, political and economic rights. The purpose of the Convention to offer a tool to effectively monitor the human rights situation of disabled people and to initiate change for the better is promising one. Before outlining the aim and method of the

current study, the following chapter provides a more in depth reflection on the right to work and employment which is the subject of the present research.

3 The right to work and employment

The reflection on the underlying principles of the Convention has shown that various and sometimes even controversial concepts exist and that a critical reflection through the lens of disability is needed to identify the most applicable for the monitoring process, as the aim of disability rights monitoring is a substantive positive change for disabled people in practice. Underlying concepts and theories do matter, as the way social phenomena are conceptualised determines the political approaches and the policies implemented (Rioux and Fraser 2006). This applies also to the concepts of work and employment. The ontologies of work and employment have changed across time, place and culture. Throughout European history various trends such as industrialisation, globalisation, digitalisation as well as demographic changes have influenced the meaning and concept of work. Focusing on the European context, the following chapter aims to, first, offer a brief insight into the changing ontologies of work and employment. In a second part, the role of critical disability studies and the efforts of disabled activists and researchers who fight for a more inclusive world of work and a radical reconceptualization of the hegemonic concepts of work are outlined. In the final section, the emergence and the drafting process of the right to work and employment as enshrined in the Convention of the Rights of Disabled People is examined. It will be shown that the right to work and employment acknowledges the special position of disabled people in the labour market and thus provides a suitable framework to critically monitor and assess the situation of disabled people in the labour market.

3.1 Work and employment – a changing social construct

In social and political discourses it is commonly agreed that work and the nature of work is a social construct that has changed throughout time, place and culture. At the beginning of the Western civilization, in Ancient Greece, work was the characteristic that excluded people from social status (Beck 2001b). Back then, work was associated with physical labour which was a symbol for oppression and usually assigned to women and slaves. In the modern age, the meaning of work changed dramatically. A major impact was provided by industrialisation and the division of the social life into the private and public realm. Whereas prior to the division into the private and public

sphere, nearly everyone (including children and disabled people) was in some way included in the daily social life, the industrialisation and the division of labour processes commodified the everyday social life. Wage labour and paid employment – or as Marx called it the "alienated labour" (McLellan 1983, 33) gained enormous influence in the public sphere (Barnes 2003a). With the ongoing rise of capitalism, work became the central aspect of social life and social identity (Abberley 2002; Beck 2001b; Galer 2012) – the work society was born:

> "The daily rhythm of work, with its discipline, its values and its conception of personal responsibility and cooperation, corresponds to the demand made by the rulers of the work society upon their workers and employees. This demand for order within the work society is still with us today - indeed, it has become part of the self-understanding of people who form, revalue and naturalize their own identity and personality only in and through work. The biblical curse morality grounding human existence; only those who work are truly human" (Beck 2001b, 13).

The quote above highlights how the participation in the workforce is an important feature of the modern European self-identity. The question "What do you do?" in initial encounters reveals the predominant role of work and employment status in the formation of a valued social identity. The assumed positive aspects of wage labour and paid employment on the individual well-being are hardly questioned. It is instead claimed that employment and paid work are key elements that contribute to the full participation of citizens in economic, social and cultural life. Employment offers the individual a sense of purposefulness and a possibility to contribute to the collective good. The structure of paid work, with its working hours, reimbursement and tax systems, regulates and organises social interactions in complex societies (Arendt 2002; Beck 2001b).

Bearing in mind that work is associated with paid employment and wage labour, people who are excluded from paid work experience social exclusion and discrimination. Thus researchers increasingly focus on the impacts of unemployment or underemployment (Beck 2001b; Jahoda 1983; Becker 2015). In her analysis "how

much work is needed? Work and unemployment in the 20th century"[27] Jahoda (1983) describes that despite all modifications two aspects of the nature of work and employment have remained constant: (1) the majority of people sustain a living on the basis of the income they gain through paid labour and (2) work provides further benefits, such as social relationships outside the family, social status and a time structure. Her research shows that at the beginning of the 19th century unemployment was mainly associated with poverty and the shortage of the most necessary things, such as food and shelter - it was a complete psychological deprivation. As more and more social benefits were provided to the unemployed, the consequences of unemployment were mitigated. Nevertheless five consequences of unemployment can still be identified today: (1) destruction of the daily structures, (2) isolation/decrease of social contacts, (3) missing of the sense of individual purpose, (4) loss of social status and prestige and (5) lack of a regular activity. These consequences often result in severe psychological stress (Jahoda 1983). Analysing the diminishing security and standardisation of work, Ulrich Beck has recently identified similar problems (Beck 2001b). Due to further globalisation trends and an increasing influence of technology, work is becoming more and more flexible and non-standard labour is increasing. This development comes along with an increase in underemployment and work arrangements that do no longer offer security, such as part-time work or temporary work (Wilton 2004; Beck 2001b). Nowadays, for many employees, work also means a life on the margins of poverty (Becker 2015, 82). As full-time employment is coming to an end, the work-centred society is losing its central meaning; Beck further claims that this development is non-reversible and thus full employment in terms we know is a utopia. To tackle these obstacles, he introduces the concept of an "active civil society" which is based on democratic structures and the inclusion of all citizens. In a civil society, individual identities are no longer shaped in terms of their participation in paid work but through a new active self-understanding of multi-faceted activities (Beck 1996, 2001b). Beck refers to Hannah Arendt's "Vita Activa" in which she makes a distinction between labour ("Arbeit"), work ("Herstellen") and action ("Handeln") (Beck 1996, 144). For Arendt, labour is a necessity for the self-preservation of the

[27] Own translation; Original title: „Wieviel Arbeit braucht der Mensch? Arbeit und Arbeitslosigkeit im 20. Jahrhundert" (Jahoda 1983).

human species. The products of labour are consumed and therefore the need to produce more is never satisfied. In contrast to labour, work has a clearly defined beginning and end. Within the process of work a durable object is produced, such as a tool, which is not consumed but becomes part of the world (Arendt 1958, 79). Action, in contrast to work and labour is a human activity that no one can escape from. It is the mean that creates human relationships and reveals the human self (Arendt 1958, 175). Arendt, as well as Beck, calls for an active civil society. Beck's concept involves a radical reduction of working hours to establish a plural 'underemployment system' that will lead to an overall increase in workforce participation combined with a comprehensive social protection mechanism. In such a system, individual identities are shaped through diverse activities, such as family work, parental work, work for oneself, voluntary work or political activity. On the core of the new social society lies the model of 'civil labour' - a form of work that is voluntary and self-organised and that means that it is "no longer just the labour market but also political life which integrates people into society, by offering (limited) material security, esteem and identity" (Beck 2001b, 140).

Despite the growing evidence that the work society as we know it is coming to an end (Beck 2001b, 1996; Wright 2013; Kronauer 2012; Barnes 2003a), wage labour and paid employment remain the main focus of social policy makers that tackle discrimination, exclusion and social injustices (OECD 2010, 11). Paid employment is considered as a mean of justice, a justitia laboris (Becker 2015, 119). Opponents of a comprehensive welfare system argue that welfare state measures are promoting dependency rather than encouraging self-responsible life style practices. Such criticism has existed since early stages of the modern welfare state[28] (Bentham 2012, 7; Hartz 1928). Recent scholarship shows that narrower perspectives of welfare state reforms on efficiency and profitability have replaced the former goals of equity and social justice (Rioux 2002; Sherry 2014; Schlund-Vials and Gill 2014). Recent cut backs on welfare expenditures and the pledge for an active citizenship has led to the introduction of the so called activation and workfare principles that have an impact on

[28] Jeremy Bentham called the declaration of the French Rights of the Man as "Nonsense on Stilts" (Bentham 2012).

many disadvantaged groups, such as women, people with caring responsibilities, immigrants and people with disabilities (Morris 2011; Sherry 2014; Schlund-Vials and Gill 2014; Beck 2001b; Silver 1994; Soldatic and Meekosha 2012; Gallie 2002; Owen and Harris 2012). The aim of such approaches is to cut back welfare expenditures and to turn welfare systems into markets wherever possible (Giddens 1995, 6). Lawrence M.Mead is perceived as one of the grounding authors aiming to justify workfare measures to achieve social citizenship (Cattacin et al. 2005, 62).

In the 1990s Mead emphasised that every social right or entitlement corresponds with certain social duties. He put an emphasis on individual obligations (Cattacin et al. 2005, 62). The main principle of workfare is work in exchange for welfare. Such an approach is said to transforms the relationship between the state and the welfare recipients, and change it from a one-sided to a reciprocal relationship (Lawrence M. Mead 1989, 164; Cattacin et al. 2005, 62–63). Work or seeking work becomes a social obligation. Mead claims that public policies in which work is something the poor *would like to do*, but not something they feel they *must* do at any cost create a "culture of poverty "and therefore needs to be changed (Lawrence M. Mead 1989, 162). Analysing the case of the black underclass in American cities, Mead blames the lack of regular engagement in work as one of the main reasons for the entrenched poverty, passivity and dependency amongst this group. He argues that the poor must become workers before they can stake larger claims to equality (Lawrence M. Mead 1989, 156). Workfare measures include all mandatory, work-related activities in which clients, welfare recipients, may engage, including training, job search, or education, as well as work" (Lawrence M. Mead 1989, 156–64). Regarding to Mead "workfare should be seen in the broadest sense as a form of public education" (Lawrence M. Mead 1989, 166).

Along with the growing influence of workfare schemes that aim to develop a new model of welfare which is 'leaner, fitter and meaner' (Atkinson 2005), widespread criticism has emerged, not only from the disability rights movement but also from other social movements. It is argued that such reciprocal welfare schemes have led to the establishment of an 'active society' (Oliver and Barnes 2012; Abberley 1987; Becker 2015). In an active society members have to engage in some kind of work in

exchange for social entitlements. Such an approach undermines the role of cultural and structural barriers, does not respect the changing nature of work and individual choices and the pluralisation of life styles (Morris 2011; Soldatic and Chapman 2010; Silver 1994; Owen and Harris 2012; Barnes 2003a; Wittig-Kope, Bremer, and Hansen 2010; Beck 2001b). Furthermore, workfare approaches fail to take into account the reasons for which welfare provision is justified in the first place (Cattacin et al. 2005, 59). At best they offer a partial solution (Gallie 2002). Implying an obligation to work entails a double punishment for many unemployed welfare recipient, because it puts the responsibility solely on the individual and thus appears to be an inadequate social policy to combat the social exclusion of the least advantaged members in societies (Cattacin et al. 2005, 64–65).

Critical thinkers offer new perspectives in this debate as they claim that policy makers need to transform the ontology of work and move on from social security systems that are based on the traditional breadwinner model and measures that presume that the market can tackle persisting inequalities (Beck 2001b; Becker 2015; Soldatic and Chapman 2010; Giddens 2002). They further claim that it is the task of governments to reduce these inequalities and provide resources to the individuals that cannot cope in the competitive market system (Giddens 2002, 35). Drawing a link between work and disability the following section shows what critical disability studies can contribute to this debate.

3.2 Work and employment through the lens of disability

> "A second aspect of our special position in society is that we are often *useless*, unable to contribute to the economic good of the community […] As such, again we cannot help posing questions about values, about what a person is, what he is for, about whether his work is the ultimate criterion of his worth, whether work in the everyday sense of the word is the most important or the only contribution anyone can make to society. There is no doubt that we do put great stress on the individual's economic contribution. Most people are wrapped up in a workday, utilitarian world, and regard anything not visibly productive as expendable. Contemplation, philosophy, wisdom, the liberal arts, get short shrift from the average man. Those who cannot work, such as the sick, aged or unemployed, are

subject to a tremendous pressure to feel useless, or at least of less value than the breadwinner" (Hunt 1966).

The quote by Hunt, formulated more than 50 years ago, still describes the social position in which many disabled people - men and women - find themselves. Recent policy developments aim to minimise the "significant burden" traditional disability benefits mean to public finances (OECD 2010, 10). Disability policies increasingly promote the concept of an active citizenship which means that participants are required to engage in some kind of work to receive social entitlements in exchange (Morris 2011; Silver 1994; Soldatic and Chapman 2010; Owen and Harris 2012; Wittig-Kope, Bremer, and Hansen 2010; Sherry 2014). As shown above such policy approaches fall too short, because the responsibility lies solely with the unemployed person (Cattacin et al. 2005, 64–65; Morris 2011). Other discriminatory issues and barriers, such as accessible transport or personal care support that might be needed within the workplace and that facilitate disabled people's employment participation are rarely acknowledged in workfare debates (Soldatic and Chapman 2010, 142; Barnes 2003a). Studies, in contrast, have shown that the extent to which employment offers opportunities for social participation depends crucially on the quality of jobs and the structural availability of labour (Gallie 2002; Wilton and Schuer 2006).

Including the perspectives of disabled people, Owen and Parker Harris (2012) explore the tension between neoliberalism and a human rights approach to disability in the context of the UK New Labour's welfare reforms for people with disabilities, from 1997 to 2010. They found that the welfare reforms were strongly influenced by neoliberalism and that welfare state retrenchment was a key feature of the reform. The impacts of neoliberalism emphasised 'no rights without responsibilities' and the recommodification of labour. Individuals were required to participate in the labour market to be considered as full citizen. However, many disabled people criticised the lack of choice in the types of available and attainable work. The authors conclude that neoliberal reforms serve to normalise people with disabilities by enforcing their participation in the labour market. Such reforms are most effective for those that are already close to the labour market, but not to all people with disabilities, in particular not to those who had very limited labour market opportunities (Owen and Harris

2012). In addition, Soldatic and Chapman show that workfare policies discriminate in particular against disabled women as the underlying citizenship models are based on able-bodied, masculine notions of care, work and productivity. They conclude that,

> "[in the] case of many disabled people who have extensive personal care needs, and especially in the case of women with disabilities who may provide multiple forms of time intensive care, for themselves and others, workfare is a highly pervasive policy strategy further stigmatizing the subjective experience of the self and the body" (Soldatic and Chapman 2010, 142).

Soldatic and Chapman further show that the disability movement has been weakened by trying to comply with the new workfare agenda. As funding schemes have focused mainly on the outcomes and service providers have, in a neoliberal manner, been privatised, the most 'able of the disabled' became the central focus of support measures (Soldatic and Chapman 2010, 144). Abberley argues that the

> "work-based model of social membership and identity is integrally linked to the prevention/cure-orientated perspective of allopathic medicine and to the specific instrumental logic of genetic engineering, abortion and euthanasia. Ultimately it involves a value-judgement upon the undesirability of impaired modes of being" (Abberley 2002, 135).

Whereas such logic might allow the integration of a certain proportion of impaired people in the world of work, it will leave many disabled people - those who cannot be integrated in the existing mode of production – in a disadvantaged position. Abberley therefore calls for:

> "An alternative kind of theory [that] can be seen as offering another future in so far as it rejects work as crucially definitional of social membership and is sceptical about some of the progressive imperatives implicit in modern science. This is by no means to deny that the origins of our oppression, even for those with jobs, lie in our historical exclusion as a group from access to work; nor is it to oppose campaigns for increasing access to employment. It is, however, to point out that a consistently liberative analysis of disablement today must recognize that full

integration of impaired people in social production can never constitute the future to which all disabled people can aspire […] One practical implication of this view is to caution against the over-enthusiastic espousal of work- based programmes for overcoming the exclusion of disabled people which leave welfare systems unchanged or, worse still, depleted" (Abberley 2002, 135–36).

In contrast to current transnational and national strategies that put entry in the workforce at the core (e.g. European Disability Strategy, German National Plan) Abberley advocates for a dual strategy, which means "work facilitation for those who want it and can meaningfully take part in the labour process and the general valorisation of non-working lives for those, including impaired people, who are unable to work" (Abberley 2002, 120). The current emphasis must shift from looking at integral rather than the integrable nature of disability to human existence. Such a shift would require a reconceptualisation of the expectations of productivity based upon the divergent capacities of the individual and of the workday itself (Mitchell 2002, xiii). In a world in which an increasing part of the population are left out of the labour market, disabled people can lead the discussion about a new meaning of social identity, one that disentangles identity and work. Such a discourse would include a recalibration of the values generally associated with waged labour namely, independence, self-reliance and productivity. The recalibration would extend worth and identity to those systemically deprived from the labour market (MacGregor 2012). Hall and Wilton argue that in recent years governments have focused mainly on improving the employability of disabled workers rather than figuring out how to make 'mainstream' workplaces more accommodating to disabled people. To address this lack in policy making, they present three alternative ways to create more accommodating work opportunities for people with a disability, namely a stronger connection between labour unions and disabled employees to ease the accommodation process; second, the provision of workplaces within non-profit organisations operating outside the 'mainstream' services, third the strengthening of alternative work spaces (Hall and Wilton 2011).

In line with Beck's aspirations of an active citizenship many disability scholars call for a radical re-appraisal of the meaning of work, an ontology that includes personal

care and care for others (Morris 2011; Barnes 2003a). Such a system would require a more equitable and less stigmatising distribution system (Barnes 2003a) and the acknowledgment that a different role of social welfare is necessary, as traditional welfare models stop when a person enters the labour market and the income is above a certain threshold. In the case of disability, it needs to be recognised that people with disabilities have ongoing medical and social support needs. Therefore measures of welfare support should continue even when a person is in employment (Quinn and Degener 2002a, 18). In regards to the debate about rights and responsibilities, Owen and Parker Harris conclude that:

> "newer efforts could take a broader view and look beyond the individual as the cause of unemployment and consider wider structural and market-based barriers. […] These suggest that 'no rights without responsibilities' can also be understood in terms of the government's responsibility. People with disabilities will find it difficult to achieve human rights unless government also fulfils its responsibilities" (Owen and Harris 2012).

To support claims of government responsibilities, data is required that shows to what extent governments fail to fulfil their obligation to address structural and market-based barriers. National and international surveys show that people with disabilities belong to the most marginalised group in the labour market (Burchardt 2000; International Labour Organisation 2004; OECD 2010; World Health Organization 2011). Focusing on the UK, Tania Burchardt examined what impact the policies designed to promote employment opportunities for disabled people had over the last 20 years. The study found that employment rates were only around 40 % and have remained stable over the last two centuries. In addition, the study found that people who become disabled while in work are more likely to lose their employment during the first year after the attained disability and to find work is more difficult for disabled jobseekers compared to the non-disabled counterparts (Burchardt 2000). Similar findings were made across OECD countries: A recent report shows that employment rates of people with disability are significantly below the overall average and unemployment rates are typically double as high as the overall level (OECD 2010, fig. 1.2).

Such quantitative data is supported by more qualitative findings. Based on semi-structured interviews, Wilton and Schuer found that due to the increasing neoliberal impacts in the labour market, such as deregulation measures and an increased focus on productivity and workers flexibility, people with disabilities find exclusionary and discriminatory workplace geographies (Wilton and Schuer 2006). Research also found that the work conditions of employed disabled people are lower compared to non-disabled workers. Many of the disabled people who are in work have low-level jobs with low incomes and with little social and legal security and low promotion prospects (United Nations 2012a, 4). In combination with additional costs some disabled people have due to impairment specific adjustments, even when employed a much higher poverty risk. Disabled people are more likely to be employment part-time or in temporary positions (Burchardt 2000; United Nations 2012a).

Considering the poor work conditions in which disabled people often find themselves (Burchardt 2000; Wilton and Schuer 2006), the term *decent work* plays a significant role, when analysing the situation of disabled people in the workforce (O´Reilly 2007). The concept of decent work was introduced by the International Labour Organisation (ILO) and it promotes an understanding of work that involves "opportunities for work that is productive and delivers a fair income, security in the workplace and social protection for families, better prospects for personal development and social integration, freedom for people to express their concerns, organise and participate in the decisions that affect their lives and equality of opportunity and treatment for all women and men" (International Labour Organisation 2016)[29]. To what extent the concept of decent work is acknowledged in the UN framework for disabled people will be outlined in the following section.

[29] For more information see ILO website: www.ilo.org/global/topics/decent-work/lang--en/index.htm [date of access: 06/06/2018]

3.3 The right to work and employment as enshrined in the disability human rights framework

Whereas article 27 of the CRPD provides the most detailed clarification of state obligations to introduce structures and legal measures that prohibit discrimination on the basis of disability in regards to all matters concerning all forms of employment, the right to work has been codified in several other international instruments. One of the earliest international acknowledgements of the right of people with disabilities to work opportunities was made by the ILO in 1944 (O´Reilly 2007, 4). The ILO introduced a recommendation that considered the situation of disabled people; it stated that disabled workers, "whatever the origin of their disability, should be provided with full opportunities for rehabilitation, specialized vocational guidance, training and retraining, and employment on useful work" (Employment (Transition from War to Peace) Recommendation, 1944 (No. 71)). Four years after the recommendation, the Universal Declaration on Human Rights (UDHR) recognizes that *everyone* has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment (Art. 23, para. 1, own emphasis). The right to work is further enshrined in the International Covenant on Economic, Social and Cultural Rights (CESCR) which guarantees in article 6 the right to work in a broad sense as well as clarifying just and favourable conditions of work in article 7 and the right to form, join and exercise trade unions in article 8. However, neither article 23 of the UDHR nor the articles 6-8 of the CECSR refer to people with disabilities explicitly[30]. This shortage caused by the lack of disability awareness at the time of the drafting processes (United Nations 1994, para. 6) was addressed in 1994 by General Comment No. 5: Person with Disabilities to the CESCR. Referring to articles 6-8 of the CESCR, the General Comment addressed the discriminatory position of disabled people in the field of employment. It stressed that the integration of disabled people in the labour market should be actively supported by the State (para. 20). Whereas equal opportunities for

[30] Other international legal instruments that codify the right to work but do not include an explicit reference to disabled people are the International Covenant on Civil and Political Civil Rights (Art. 8, para. 3 (a)); the International Convention on the Elimination of All Forms of Racial Discrimination (art. 5, para. (e) (i)); the Convention on the Elimination of All Forms of Discrimination against Women (art. 11, para. 1 (a)); the Convention on the Rights of the Child (art. 32); and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (arts. 11, 25, 26, 40, 52 and 54). For an overview on several regional legal instruments see (United Nations 2012b)

productive and gainful employment in the labour market are emphasised (para. 22), the provision of sheltered facilities with no real alternatives in the open labour market is classified as a violation of the right to work (para. 21). Accessibility and barriers removal are also addressed in paragraphs 21 and 22. Being a non-binding instrument, Comment No. 5 makes a reference to the ILO Convention No. 159 (1985) concerning vocational rehabilitation and employment of persons with disabilities. The ILO Vocational Rehabilitation and Employment (Disabled Persons) Convention (No. 159) of 1983 was the first international legally binding instrument that promoted the employment of disabled people in the open labour market[31]. More recently the Economic and Social Council has addressed the issue of disability in regards to work and employment in its General Comment No. 23 on the right to just and favourable conditions of work (2016). Explicitly referring to disabled workers, the Committee on Economic, Social and Cultural Rights acknowledges in General Comment No.23 that workers with disabilites require specific measures to enjoy the right to just and favourable conditions of work on an equal basis with others. Once more the matter of sheltered employment is highlighted. It is claimed that workers with disabilities should not be segregated in sheltered workshops but should benefit from an accessible work environment in which reasonble accommodation is provided (General Comment 23, para. 47(c)).

Article 27 stresses that the right to work and employment includes "the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in the labour market" (CRPD, Article 27, para. 1). The CRPD does not introduce any new rights but clarifies the obligations States have to safeguard and promote the realisation of existing human rights and fundamental freedoms as defined in the International Bill of Human Rights. The UN claims that the right to work is essential for the realisation of other human rights and forms an inseparable and inherent part of human dignity. Work is meant to provide livelihood to the person and her or his family, and if work is freely chosen or accepted, it contributes to the person's personal development and

[31] Both Germany and Portugal have ratified the ILO Convention No. 159. Germany has ratified it on 14 November 1989 and Portugal has ratified it on 03 May 1999.

social recognition within the community (United Nations 2012a, 3). In her analysis of article 27 of the CRPD, Ferraina shows that throughout the negotiation and drafting process of article 27 there have been controversial positions about the inclusion of sheltered employment. For instance, the International Disability Alliance opposed a legal justification of sheltered employment arguing that the "right to free choice of employment, to just and favourable conditions of work is denied among others by being relegated to sheltered workshops" (International Disability Alliance cited in (Ferraina 2012, 26)). In contrast to this negative stance concerning sheltered employment, the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities of 1993 listed sheltered workshops amongst other options of employment in the case when the open labour market proved not to be feasible for people with disabilities (Paragraph 7). The CRPD, and none of the draft texts of the article on work and employment, included a reference to sheltered employment. In doing so the Convention adopted the view that sheltered workshops are against the inclusive ethos of the Convention, as they segregate people with disabilities from the mainstream society. Priestley summarises the status of sheltered employment through the lens of the UN CRPD as follows:

> "…disabled people have the same rights as everyone to be included in the same labour market (this human rights approach does not seek to recognise the creation of separate or segregated employment for disabled people ….) In principle, the concept of forced separation of disabled people into a sheltered/segregated employment market would be in conflict with the UN CRPD" (Priestley, cited in (Ferraina 2012, 31)).

Article 27 requires States Parties to recognize the right of persons with disabilities to work "in a labour and work environment that is *open*, *inclusive* and *accessible* to persons with disabilities" (CRPD, Article 27, para. 1, own emphasis). To achieve this objective, State Parties shall safeguard and promote the realisation of the right to work including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

(a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;

(b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;

(c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;

(d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;

(e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;

(f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;

(g) Employ persons with disabilities in the public sector;

(h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;

(i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;

(j) Promote the acquisition by persons with disabilities of work experience in the open labour market;

(k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities. (CRPD, Article 27, para. 1)

In addition, State Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour (Article, 27, sentence 2). Being the most recent, legally binding instrument, the CRPD plays a significant role in the monitoring process of the right to work and employment and its translation and implementation in practice.

Final remarks

The present chapter has outlined how the concepts of work and employment have changed across time, place and culture. While at the beginning of the Western civilization work was the characteristic which excluded people from social status, work and employment have become central aspects of a valued social identity in contemporary societies (Beck 2001b). More recently, determining who is entitled to citizenship status, workfare approaches have become predominant in many western societies. It has been shown that such workfare measures often fail in the context of disabled people, a group that belongs to the most marginalised in the labour market. Disability activists therefore call for a dual strategy and a radical transformation of the ontologies of work and employment (Abberley 2002; Soldatic and Chapman 2010; Becker 2015). To sustain such claims information about the situation of disabled people in the labour market is needed. The chapter has shown that the emergence and the drafting of the right to work and employment, as enshrined in the Convention of the Rights of Disabled People, has been a lengthy process. By acknowledging the special disadvantaged position of disabled people in current labour processes, the right to work and employment, in combination with the underlying human rights principles, offers a framework to critically monitor and assess the situation of disabled people in the labour market which is the aim of this paper. The next chapter outlines the methodology of the present research in more detail.

4 Aims and method

"We believe that the outcome of good research is not just books and academic papers, but is also the creative action of people to address matters that are important to them. Of course, it is concerned too with revisioning our understanding of our world, as well as transforming practice within it" (Heron and Reason 2001, 179).

4.1 Aims of the study

As shown in chapter one, critical (disability) theory condemns the passive character of traditional social science and argues instead for an epistemological approach that has a practical, emancipatory interest (Habermas 1971; Hosking 2008; Alway 1995). As further shown in chapter two, it has been a long fight for disabled people and their supporters to have their human rights enshrined in an international legally binding instrument. The monitoring obligation of the Convention requires State Parties not only to maintain, strengthen, designate or establish a human rights framework, but also to monitor its implementation. As Pinto claims human rights monitoring is the activity that enables societies to evaluate whether progress in securing rights has taken place and it further provides information about existing gaps (Pinto 2011b). The present analysis aims to critically reflect on the right to work and employment in the German and Portuguese context. The study is guided by the following research questions:

- How is the right to work and employment (CRPD) translated into national laws, policies and programmes in the German and in the Portuguese context?

- How do people with disabilities in Germany and in Portugal experience the fulfilment of the right to work and employment in practice?

- What can we learn from the German and Portuguese cases to inform future policy development in this area that advances the right to work for people with disabilities in Germany, Portugal and beyond?

The two first questions aim to contribute to the overall objective of the research which is a *comparative analysis* between Portugal and Germany. The comparative perspective of the study intents to *identify best practice policies that can influence future policy* development in Germany, Portugal and beyond (question three).

In the following paragraphs I will outline the methodological approach of the present study. First, I will elaborate on the choice of the research strategy. Then, the data collection and the data analysis methods will be explained. In the final part of the chapter, I will elaborate on the comparative perspective of the study.

4.2 Methodology – an emancipatory research approach

> "Relevant research in this field [disability studies] needs to be concerned with the struggle for change and ... material and ideological barriers to participation... relevant research is essentially transformative, informative, contributing to the collective experience and understanding of disabled people over the ways in which disability is socially produced" (Barton 2005, 318).

In contrast to traditional research paradigms which aim to understand and explain the world, critical research agendas are underlined by an emancipatory cognitive interest (Habermas 1971). Outlining the historical changes of research production in social science in general, and its impacts on disability research in particular, Oliver argues that both the positivist and the interpretive paradigm produce alienating research and that only emancipatory research "can challenge the social relations of research production" (Oliver 1992, 112). Throughout history, disabled people have been treated as objects rather than as subjects in disability research (Abberley 2002; Oliver 1992; Barnes and Mercer 1997; Barnes 2003b). The predominant research paradigm, in which people with disabilities are seen as research objects, has only been challenged lately (Barnes 2003b). The dispute in the 1960s between disabled residents of a care home (Court Cheshire Home) who participated in a research project and who demanded greater control over their own lives, and the researcher from the Tavistock Institute who recommended instead a return to traditional paternalistic care practices is often described as an initial attempt of disabled people to change traditional

research approaches (Fontes, Martins, and Hespanha 2014, 851). As Barnes and Mercer outline "to understand the social world, it is necessary to explore people's subjective 'definition of the situation and their attempts to navigate its inherent uncertainties and dilemmas" (Barnes and Mercer 2010, 5). People's subjective definition can only be explored by listening to their narratives. In participatory research, "ordinary" people generate knowledge addressing their concerns as members of society (Park 2001). Participatory research, therefore, is a pre-requisite to ´emancipatory` research (Barton 2005). In contrast to previous research agendas, emancipatory research offers a promising possibility to empower people with disabilities and achieve positive change (Barnes 2003b; C. Marshall and Rossmann 2016; Heron and Reason 2001). In the emancipatory paradigm, disability is seen as a political issue and disability policy is seen as a means to change social structures (Oliver 1992; Barnes and Mercer 1997; Barnes 2003b).

Disability and the discrimination and exclusion of people with disabilities from the labour market are a worldwide phenomenon. The present project is inspired by the methodological approach of the international project "Disability Rights Promotion International". Disability Rights Promotion International (DRPI) is a collaborative initiative which builds on a comprehensive, sustainable international system to monitor human rights of people with disabilities[32]. Ever since it was established in 2000, DRPI has been built on the collaboration amongst researchers, disabled people and disability organisations from all parts of the world (Pinto 2011b). As Pinto outlines the critical goal of human rights monitoring is to contribute to the improvement of human rights protection in a particular country or region. In this sense, human rights monitoring is intended to bring about social change:

> "By documenting and illustrating incidences of abuse against persons with disabilities, monitoring projects will enable us to gather arguments and issue recommendations about what should be changed in the law, its application, and the workings of state institutions to eliminate discrimination and prevent rights

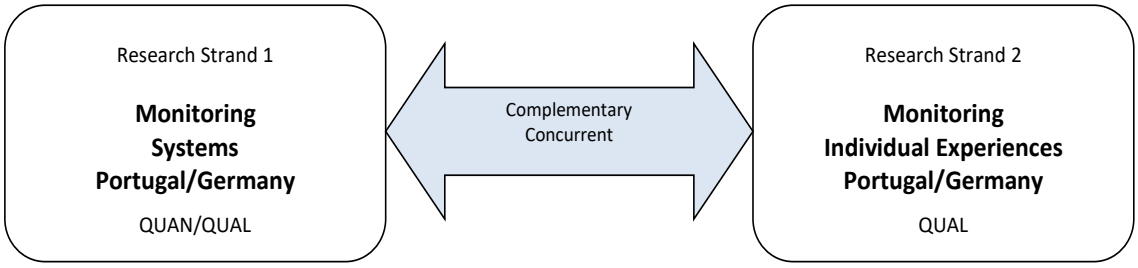
[32] More information about DRPI is available online at http://drpi.research.yorku.ca/ [date of access: 25/09/2018]

violations from occurring. Monitoring is therefore a fundamental tool to encourage and pressure governments into adopting and implementing human rights standards when dealing with their disabled citizens" (Pinto 2011b, 456).

4.2.1 Monitoring disability rights: a mixed data-collection study

As depicted in figure 2 (see below), the present monitoring process was dualistic and encompassed two areas: systems monitoring (research strand 1) and individual experiences monitoring (research strand 2)[33]. While the monitoring of systems involves collecting and studying legislative frameworks, government policies, programmes and practices that protect and enforce or violate the right of work and employment for people with disabilities, the monitoring of individual experiences means to include the narratives and voices of disabled people. The figure below shows that both research strands have been conducted concurrently with the aim to produce complementary results.

Figure 2: The dualistic monitoring process



Using both qualitative and quantitative data, the present study is defined as a mixed data study (Small 2011). Mixed methods studies are deemed to achieve results that are closer to the 'truth', as the use of mixed methods offers the potential to reflect from various perspectives and multiple world-views. Consequently, such an approach is more valid to represent the multifaceted and complex character of social phenomena (Greene 2008, 20). The so called "mixed method studies" have only emerged in the last 30 years as an alternative to the mono-method studies (Tashakkori

[33] The DRPI has adopted *three* broad areas for monitoring: systems, individual experiences and the media. Although the media has a powerful influence on the way disability is perceived and on the attitudes of the public towards people with disabilities, the present study does not include media monitoring due to limited availability of resources, both in economic and temporal terms.

and Teddie 1998; Small 2011; Bryman 2012; Collins and O´Cathain 2009). Nowadays, a growing number of researchers are combining the advantages of quantitative and qualitative methods (Small 2011; Collins and O´Cathain 2009; Greene 2008; Bryman 2012). Within the present study both monitoring processes – the monitoring of systems and the monitoring of individual experiences - were conducted concurrently. The mixed method design used was therefore the "parallel" one (Tashakkori and Teddie 1998, 18) and the purpose for the intermethod mixing was complementary (Tashakkori and Teddie 1998, 43; Small 2011, 63). Within the first research strand, an 'intramethod mixing', defined as the concurrent or sequential use of single methods that includes both qualitative and quantitative components (B. Johnson and Turner 2003), was also developed.

4.2.2 Monitoring systems

As already pointed out, since its adoption in 2006, the Convention on the Rights of Persons with Disabilities has become the blueprint and guideline for disability policies worldwide. Signatory governments of the Convention, such as Portugal and Germany, have an increased obligation to translate the rights enshrined in the treaty in national laws, policies and programmes. For the present research, the monitoring of systems involves collecting and studying legislative frameworks, government policies, programmes and practices that protect and enforce or violate the right to work and employment for people with disabilities. In this study, the documental analysis of existing legislation, policies, programmes, case law and practices was complemented through secondary analyses of existing quantitative and qualitative data, retrieved from national statistics, such as annual labour market statistics and other studies that evaluate and examine the situation of disabled people in the area of work and employment. Overall the data collected in the first research strand aimed to reflect on the “political” effectiveness of the CRPD at domestic level (Gubbels 2017).

4.2.3 Monitoring individual experiences

While existing legislation, policies and programmes may aim to protect the human rights of persons with disabilities in theory, the practical implementation often differs. Questioning “why it is so difficult to implement the CRPD?”, André Gubbels

distinguishes between three forms of legislation effectiveness : (1) “Political” effectiveness which can be defined as the degree to which the legislation at national level embodies the values and standards of the CRPD, (2) “Formal” effectiveness which can be defined as the degree to which the key provisions of the legislation are practically enforced and complied with, (3) “Substantive” effectiveness which can be defined as the degree to which legislation and the practical application of the measures at national level produce a real positive change for disabled people. He further argues that the ultimate test for a legislation that aims to implement the CRPD is its *substantive effectiveness* (Gubbels 2017). Whereas political effectiveness can be analysed through documental analysis, formal, and in particular, substantive effectiveness require the inclusion of disabled people’s voices. Exploring disability narratives in human rights discourses and monitoring projects, Titchosky argues that monitoring projects who use qualitative methods and include disabled people and their voices in the monitoring process offer the opportunity to influence the perceptions of what is perceived as human and who is considered as citizen, as rights holder (Titchosky 2014). Moreover, by including disabled people’s subjective definition of the situation in the research process, the emancipatory vision entailed in critical theory can be realised (Barnes and Mercer 2010).

The data collected in the second research strand was gathered through semi-structured in-depth interviews. The semi-structured interviews were guided through a set of closed and open questions, which were adopted from the original DRPI interview guide and which were amended for the present purpose. Whereas the semi-structured DRPI interview began with two comprehensive questions: “What has given you the most satisfaction in life in the last five years?" and "What are the main obstacles or barriers that you have had to face?”, the interview guide of the present study put the focus on work and employment; therefore, the first two questions inquired: “Please tell me a little about your working life. What kind of work have you been doing?” and “Over the last five years do you recall a particular time or event regarding work and employment when you were left out or treated differently or prevented from participating in work because of your disability?” Based on the experiences that the interviewees shared with the interviewer, the major part of the interview guide

included less structured open-ended questions that allowed to investigate issues and areas that came up during the interview process and had not been thought about prior to the interviews (Hopf 1995, 177). At the end of the interview, a set of closed questions inquired about socio-demographic information of the person interviewed, such as sex, age, type of disabilities, employment status, and academic qualification. The advantage of using such closed questions was that the data collected provided a level of comparativeness (Bryman 2012, 210). The data collected through the open-ended questions was of qualitative nature and provided a comprehensive picture of the *de facto* situation regarding the access and exercise of the right to work and employment of persons with disabilities (B. Johnson and Turner 2003). Prior to the interview, the research participants were informed about the purpose of the study. Interviews were only conducted with the free and informed consent of the participants and they were conducted in an accessible mode, for example by using simple language or a sign language interpreter whenever necessary. On average, interviews lasted about an hour and were digitally recorded. Before analysing the interviews the audio material was transcribed anonymously to protect the identity of the study participants.

4.2.3.1 Sampling/Case Selection

Since the study focused on Article 27 "Work and Employment", sampling was defined as people aged between 18 and 64 who live in Germany or Portugal and who experience some kind of disability. A “purposive sampling” (C. Marshall and Rossmann 2016, 113–16) was recruited through a mixed approach combining the snowball technique, a sampling strategy recognised as able to reach difficult to access and marginalized groups (Arber 2001, 62–63) and a statistically non-representative stratified sampling technique (Trost 1986). Whereas the snowball technique uses insider knowledge to maximize the chance that units included in the final sample are highly appropriate cases (Kemper, Stringfield, and Teddie 2003, 283), Trost's (1986) technique ensures that the participants represent the maximum diversity in the independent variables most relevant to the study objectives. Disability is an intersectional experience; studies show that, for example, women with disabilities are often further disadvantaged than their male counterparts (Soldatic and Chapman 2010; Pinto 2012). Thus, following variables were identified as relevant for the present

study: age, gender, and type of disability. In total 38 persons with a disability were willing to participate in the study; 22 interviews were conducted in Portugal and 16 people were interviewed in Germany. The participants self-identified as persons with disabilities and indicated the impairment(s) they experienced. While the study sample is not statistically representative of either the German or the Portuguese disabled population, the size of the sample was considered appropriate to the nature and scope of the research, which was limited in the availability of resources, both in economic and temporal terms.

4.2.3.2 The Portuguese Sample

In Portugal, 22 interviews were conducted in three regions of Portugal: Porto (9 interviews), Lisbon (12 interviews) and the Algarve (1 interview). Whereas 7 out of the 22 interviews in Portugal took place solely for the present study, 15 interviews had been conducted during the DRPI project in Portugal. For the DRPI study, 28 adults were interviewed using the DRPI interview guide[34]. Conducted in 2011/12, the DRPI Portugal project covered all human rights areas and was not limited to the right to work and employment. Its aim was to find out the extent to which people with disabilities are able to exercise their citizenship rights and to uncover the barriers that exist. The transcriptions of the DRPI interviews offered valuable information about human rights violations in different life domains. For the present study, the DRPI transcriptions were examined and 15 interviews were identified, in which the interviewees reported human rights issues in the life domain of work and employment. These interviews were considered suitable for the present research. The DRPI interviews were conducted shortly after the economic crisis when unemployment rates were at a peak in Portugal and public expenditures had been cut in several areas, including vocational training and employment for disabled people (Pinto and Teixeira 2012a; Pinto 2018). To enhance the Portuguese sample, additional interview participants were recruited and seven additional interviews were conducted in September 2015. All interviews except two (which were conducted in English) were conducted in Portuguese. The

[34] For more information see DRPI Portugal – Final report. Report available online at http://capp.iscsp.ulisboa.pt./en/disability-rights-promotion-international-portugal [date of access 13/05/2017)

quotes used in this paper were translated into English. The sample stratifications are outlined in tables below.

Table 1: Sample Characteristics Interview participants in Portugal

Socio-demographic indicators	Absolute Values (n=22)	Percentage
Sex		
Male	14	63.63 %
Female	8	36.37 %
Age group		
18-35	8	36.36 %
36-49	9	40.91 %
50-64	5	22.73 %
Type of Disability		
intellectual	4	18.18 %
physical	7	31.82 %
psycho-social	4	18.18 %
sensory	7	31.82 %

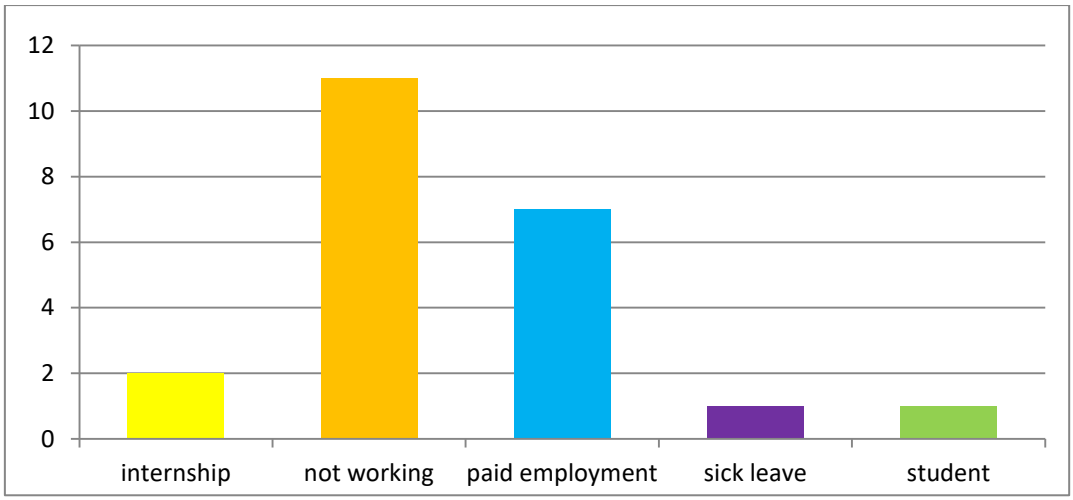
Table 2: Two rounds of interviews, sample characteristics in Portugal

DRPI interviews			Second round of interviews		
Socio-demographic indicators	**Absolute Values (n=15)**	**Percentage**	**Socio-demographic indicators**	**Absolute Values (n=7)**	**Percentage**
Sex					
Male	11	73.33 %	Male	3	42.86 %
Female	4	26.67 %	Female	4	57.14 %
Age group					
18-35	6	40.00 %	18-35	2	28.57 %
36-49	6	40.00 %	36-49	3	42.86 %
50-64	3	20.00 %	50-64	2	28.57 %
Type of Disability					
intellectual	4	26.67 %	intellectual	0	0.00 %
physical	3	20.00 %	physical	4	57.14 %
psycho-social	3	20.00 %	psycho-social	1	14.29 %
sensory	5	33.33 %	sensory	2	28.57 %

The total sample in Portugal comprised an adult population of both sexes, aged between 25 and 58 years. There were more interviews with male participants (n=14) than with female (n=8). People aged between 36-49 years represented the largest group (in total 9 interviewees). All types of disability were represented, with a higher prevalence of physical impairments and sensory impairments (7 participants in each

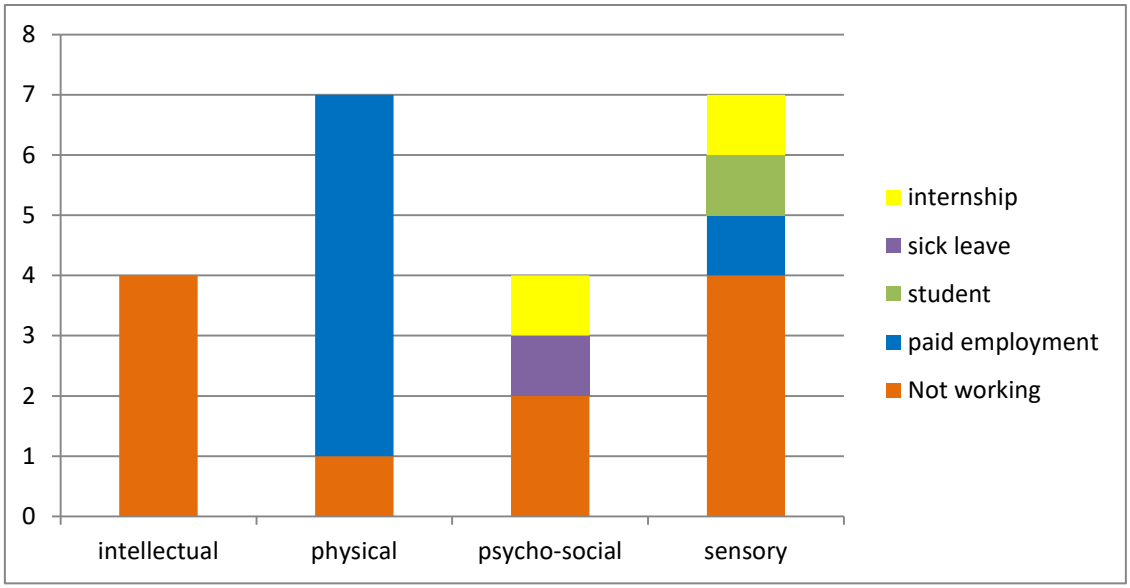
group) and a lower prevalence of intellectual and psycho-social impairments (4 participants in each group). Whereas half of the interviewees (n=11) were not working at the time of the interview, seven were in paid occupation in the open labour market , two were doing an internship, one was on long term sick leave and one was a student (see graph 1).

Graph 1: Occupation status in the Portuguese sample



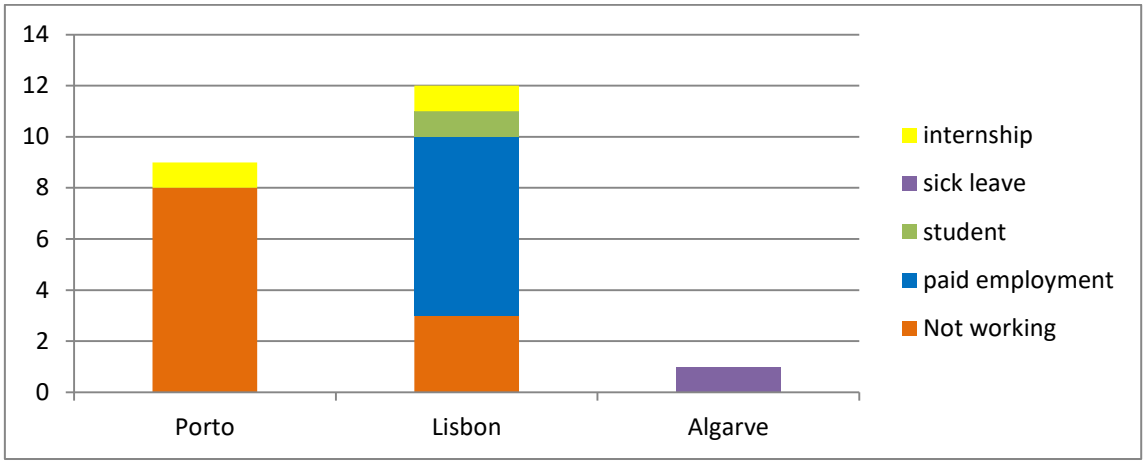
Differences in the employment status become obvious when we compare the occupation status with the type of disability. In the Portuguese sample the majority of people with physical impairments (six out of seven) were in paid employment. Only one interviewee with a physical impairment was unemployed. In contrast, all four interviewees with an intellectual disability were not working and none of the interviewees with a psycho-social disability was in paid employment at the time of the interview. The majority of people with a sensory disability (four out of seven) were not working either (see graph 2).

Graph 2: Occupations status by type of disability in the Portuguese sample



If we compare the region where the interviewees live and the occupation status, the numbers show that all interviewees working in the open labour market live in the Lisbon region. In contrast, eight of nine interviewees who live in the area of Porto were not working (see graph 3).

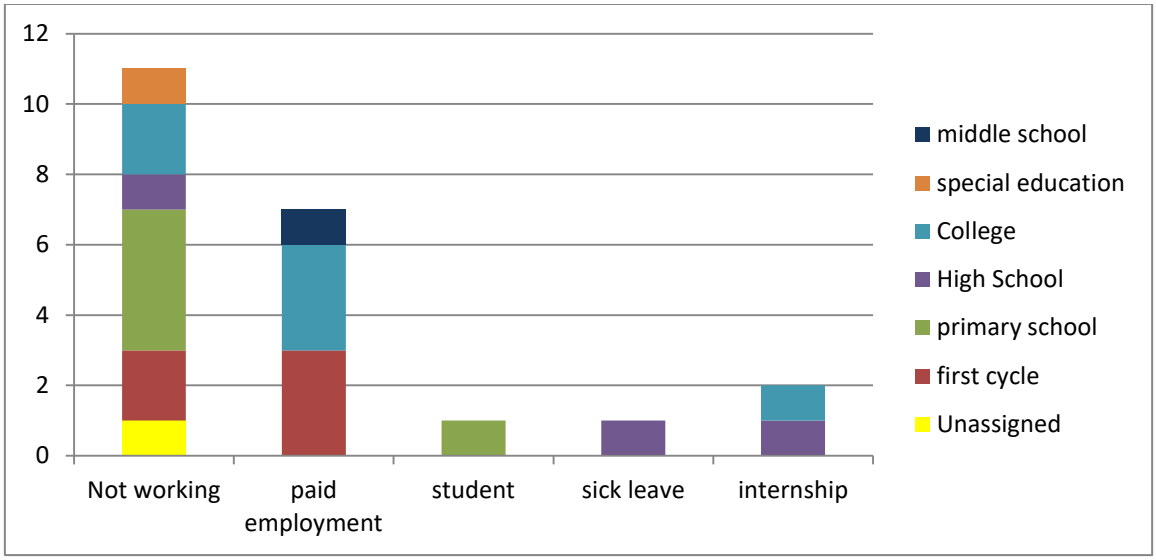
Graph 3: Occupation status of the Portuguese sample by region



Furthermore, all participants who reported that they were employed in the open labour market have a school education. The academic qualifications of the participants who are unemployed range from primary school education (4 interviewees) to University degrees (n=2) and high school degrees (n=1) (see graph below). In short,

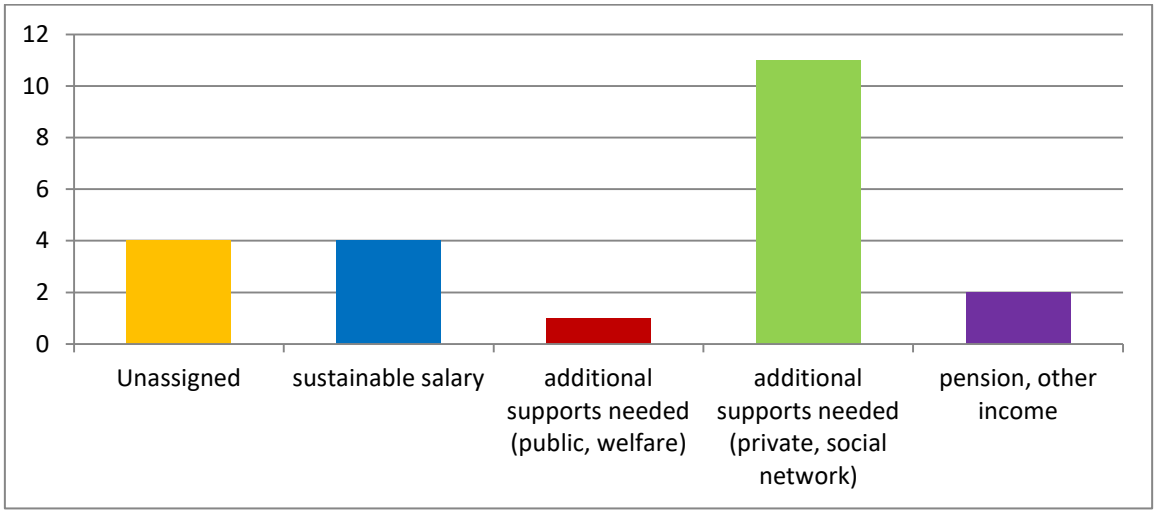
considering their occupation status, these participants represent a privileged group when compared to the mostly uneducated disabled population in Portugal.

Graph 4: Academic qualification and employment status in the Portuguese sample



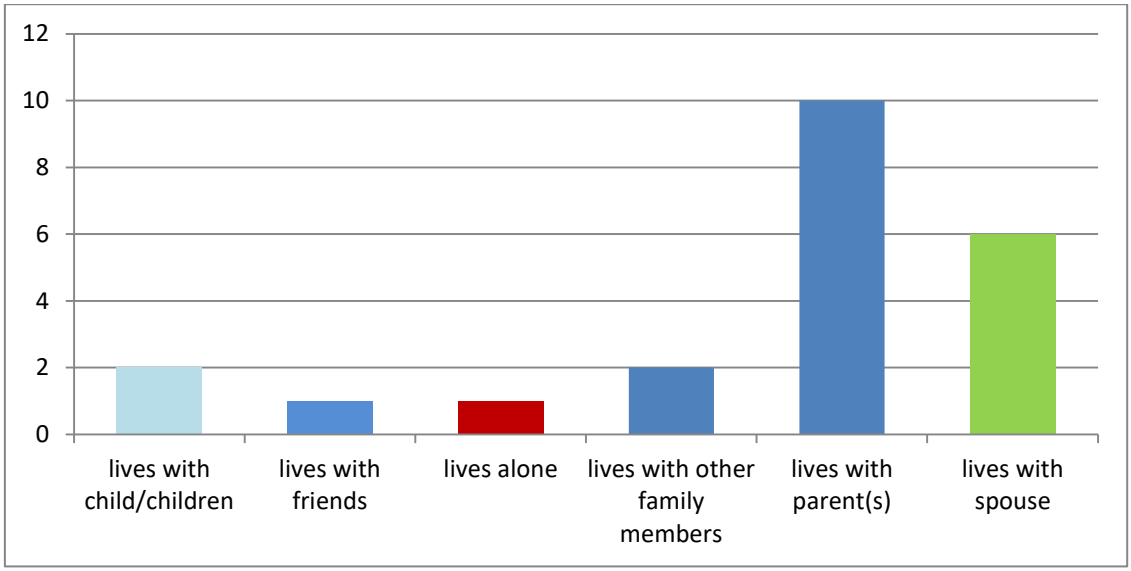
Considering that half of the participants are not working, it is no surprise that the majority of them depend on additional income support. Only four participants disclosed that they have a sustainable income. The majority (14 interviewees) stated that they depend on additional support, either from family members or friends (n=11), pension payments (n=2) or public support systems (n=1). These numbers are striking compared to Germany where 50 % of the participants received state support (see below).

Graph 5: Source of income in the Portuguese sample



In addition, the majority of the Portuguese participants live with family members. Although already adult grown-ups, 10 participants still live with their parents; two live with their children and two with other family members. Only one participant lived by him/herself.

Graph 6: Living arrangements of the Portuguese interviewees



4.2.3.3 The German Sample

In Germany no previous DRPI study took place, therefore all 16 interviews were conducted for the present study. All interviews were conducted in the Southern part of Germany[35]. As in Portugal the snowball technique proofed useful to gather a purposeful sampling. At the start, different organisations and public bodies working with persons with disabilities were approached to recruit study participants. In the end 16 participants were recruited who had some first-hand experience in the area of work and employment. The interviews were conducted in German and the quotes used in this paper were translated into English The sample was balanced and diversified for the following three independent variables considered relevant to this research: age, gender and type of disability (see table below).

Table 3: Sample characteristics Germany

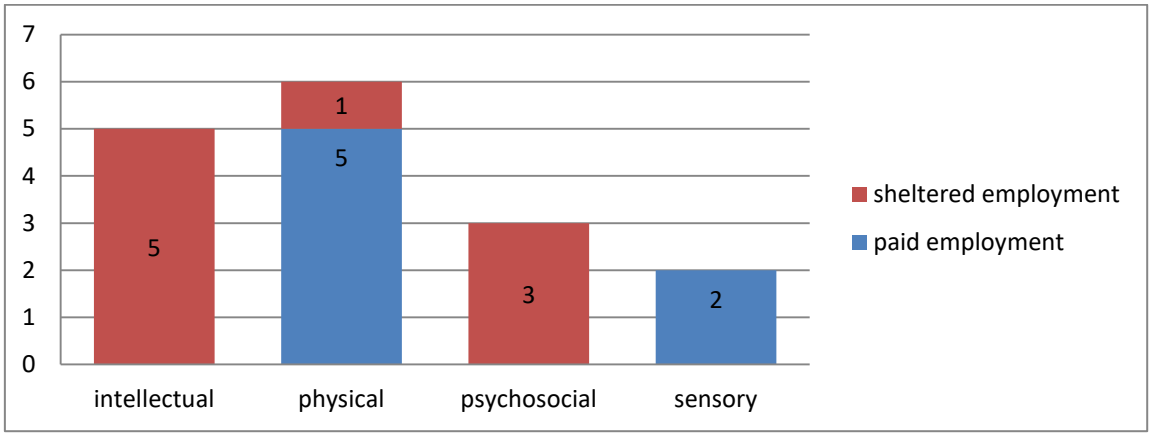
Socio-demographic indicators	Absolute Values	Percentage

[35] 15 interviews have been conducted in Baden-Württemberg and 1 in Bavaria

Sex		
Male	7	43.75%
Female	9	56.25%
Age group		
18-35	5	31,25%
36-49	5	31,25%
50-64	6	37,5%
Type of Disability		
intellectual	5	31,25%
physical	6	37.50%
psycho-social	3	18.75%
sensory	2	12.50%

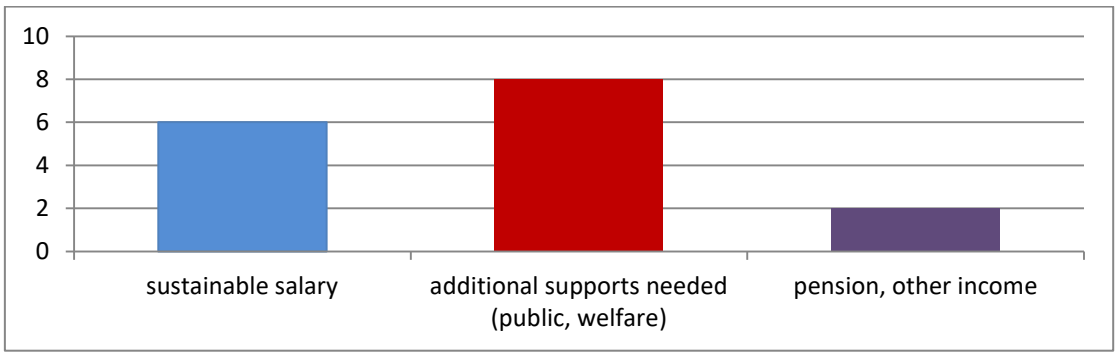
The German sample comprises an adult population of both sexes aged between 22 and 63 years. Among the interviewees there were nine female participants and seven male participants. All types of disability are represented with a higher prevalence of physical impairments (6 participants) and the lowest prevalence of sensory impairments (2 participants). In regard to the occupation status, the majority of participants (9 persons) were working in sheltered employment; the remaining seven participants had a paid occupation in the open labour market at the time of the interview. Comparing the occupation status with the type of disability, the sample suggests a relationship between the type of disability and the occupation status (see graph 7): all participants who had an intellectual or psycho-social disability were in sheltered employment, whereas five of the six participants with a physical disability and all participants with a sensory disability had a paid occupation in the open labour market.

Graph 7: Occupation status by type of disability in the German sample

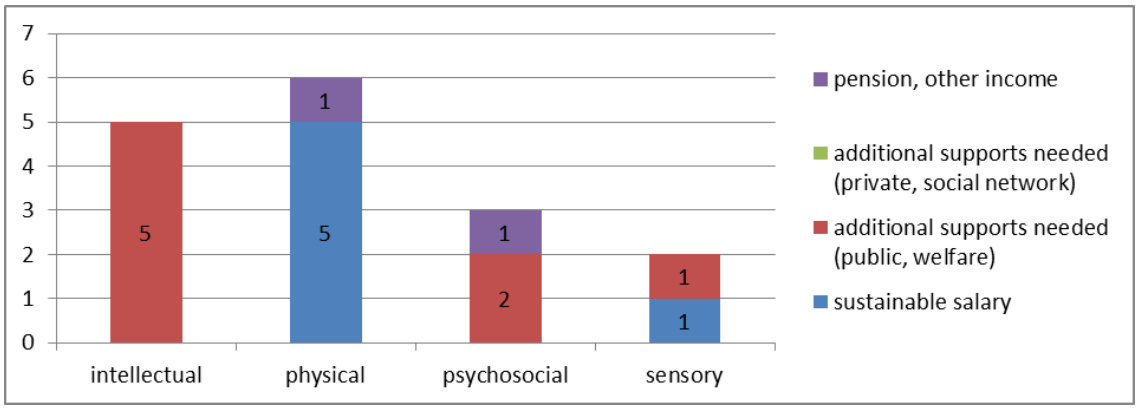


As the income in sheltered workshops is very low, it is not surprising that eight study participants depended on additional income support, six interviewees had a sustainable salary and two participants relied on a pension[36].

Graph 8: Source of income in the German sample



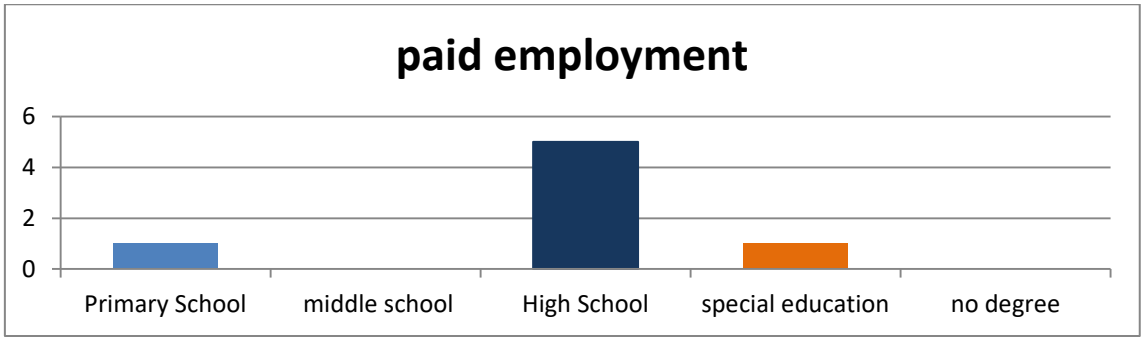
Graph 9: Source of income by type of disability in the German sample



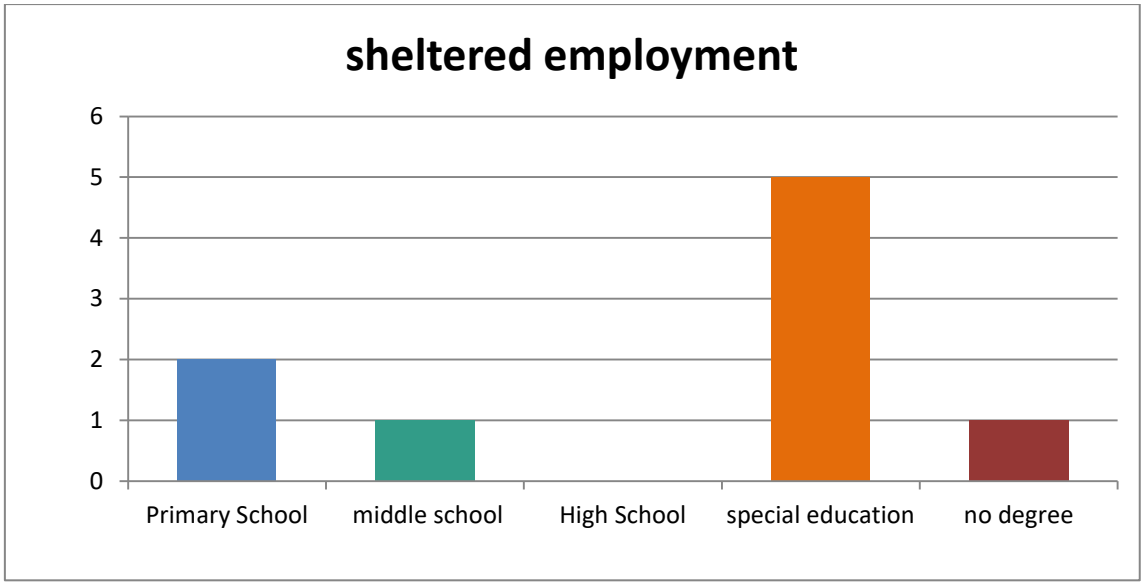
The relation between the academic qualification and the work status is outlined in the graphs 10 and 11. Only one person in the sample with a special education degree (Förderschulabschluss) was working in the open labour market. Of the nine interviewees who were working in sheltered employment, five had a special education degree, one had no degree, two were attending school until year 9 (primary school) and one interviewee was attending school until year 10 (middle school).

[36] The comprehensive government report on the participation of disabled people outlines that whereas 74% percent of the non-disabled working age population sustains a living through the income they gain through work and employment, only 40% of people with disability claim that wages are the main source of income (BMAS 2016, 155).

Graph 10: Academic qualification and employment status in the German sample, participants in paid employment



Graph 11: Academic qualification and employment status in the German sample, participants in sheltered workshops



A comprehensive study about the 'development of the admission numbers of sheltered workshops', conducted in 2006, revealed that around 41% of the people who start working in a sheltered workshop are admitted directly to the workshop from a special school and the majority of this group has an intellectual disability (Detmar et al. 2008, 7)[37]. The report further revealed that the majority of people who have been working in the open labour market prior to their admission to a sheltered workshop have a psycho-social disability (Detmar et al. 2008, 9). Among the study participants, two of the three interviewees who have a psycho-social disability have been working in the open labour market prior to their admission to a sheltered workshop. The two

[37] Two of the interviewees with an intellectual disability have been directly admitted from the special school to the sheltered workshop (EU.GE.BW.A.04 and EU.GE.BW.A.05).

interviewees disclosed that prior to their admission to the sheltered workshop they both experienced long periods of unemployment in which they were undergoing medical treatments and diverse rehabilitation therapies.

4.2.4 Data analysis procedures

In research strand 1 (systems' Monitoring) relevant legislative frameworks, government policies, and programmes that protect and enforce or violate the right to work and employment were analysed using the method of qualitative documental analysis; wherever data was available, secondary analysis were conducted on available statistics and recently published studies. The data collected through the in-depth interviews, the *de facto* data, was analysed according to an adapted version of the DRPI coding scheme, with the support of NVivo 10, a computer software also used by DRPI projects to code and organise the information from the individual interviews. The purpose of coding is on the one hand to interpret the meaning of what is said during an interview and on the other hand, as Glaser and Strauss claim, to convert qualitative data into quantifiable data that offers the possibility for comparative methods (Glaser and Strauss 1967, 102; Mayring 2002). The benefit of using an existing instrument is that results can be used for further comparative analysis with previous or future studies. The DRPI coding grid is organised into categories and subcategories. In addition to the socio-demographic variables, the DRPI Coding Scheme comprises five main themes:

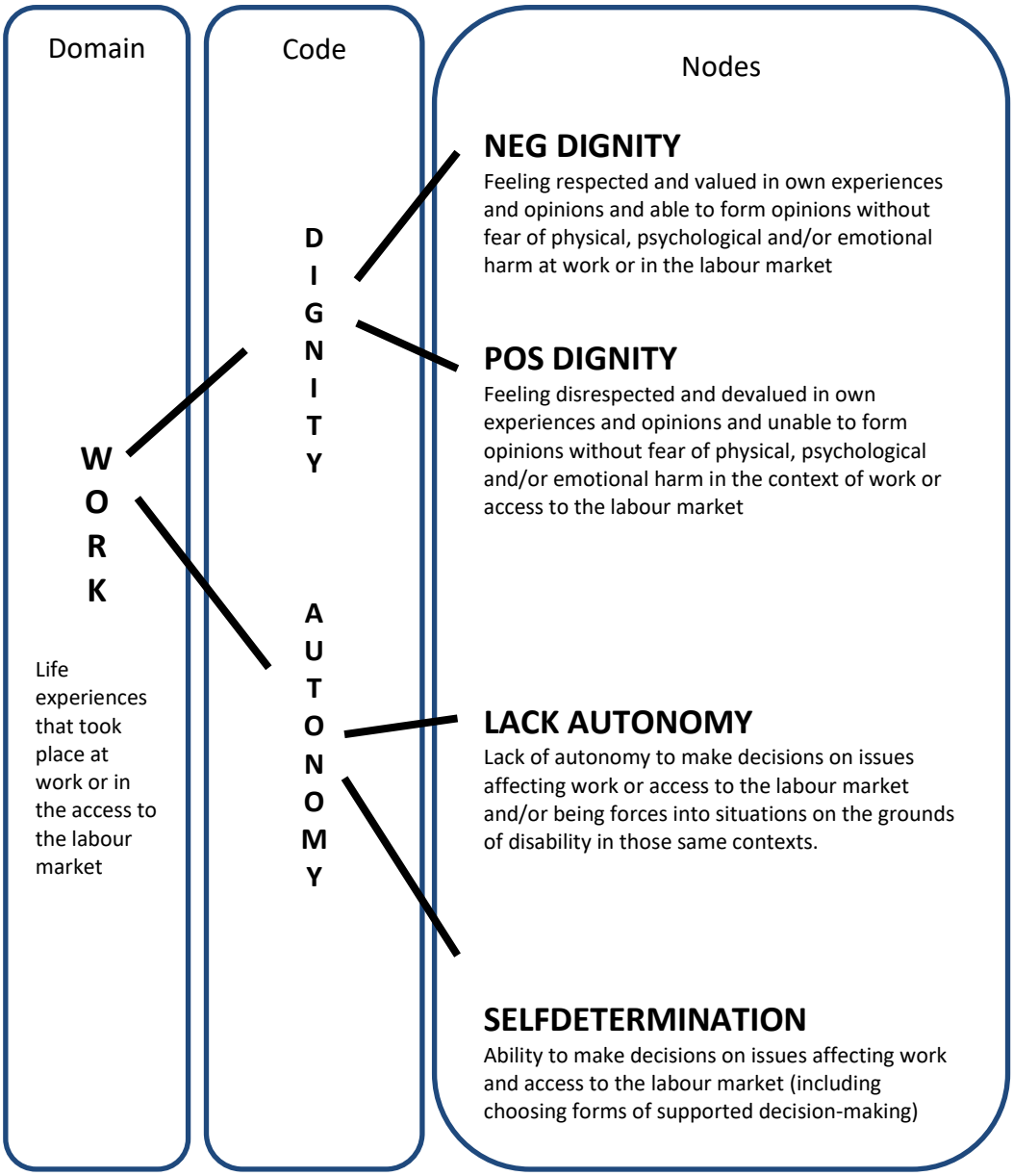
- Human Rights Implications in regards to Article 27 of the CRPD
- Responses to Abuse and Discrimination,
- Reasons for Not Reporting situations of abuse and discrimination,
- Systemic Roots of Discrimination, and
- Recommendations to improve the human rights situation of persons with disabilities.

There are also additional codes (relationships) that are used to capture information that allows the researcher to compare the treatment given to persons with disability with other more disadvantaged groups (racial/ethnic groups, women vs. men, poor

people vs. rich people). In the present research an intersectional analysis has been conducted in regard to gender and age (see chapter 8).

The domain “Human Rights Implication” is subdivided along five human rights principles: “Dignity”, “Autonomy”, “Participation, Inclusion and Accessibility”, “Non-Discrimination and Equality”, and “Respect for Difference”. Each of these codes is then subdivided into subcategories, a positive and a negative one that identifies whether a person has for example experienced a lack of autonomy in a specific situation or whether his or her autonomy has been promoted (see figure 3).

Figure 3: Coding Grid, Individual Monitoring



The following codes have been used to identify human rights violations (see also chapter 2.2):

Negative Dignity: Feeling *disrespected* and *devalued* in own experiences and opinions and unable to form opinions without fear of *physical*, *psychological* and/or *emotional harm* in the context of work or access to the labour market. This code was used whenever the person with disabilities reported experiencing *hurt feelings* (e.g.

sadness, grief, despair, depression, low self-esteem; lack of confidence) in consequence of disrespectful treatment suffered on the basis of the disability.

Lack of Autonomy: Being unable or prevented from making decisions on issues affecting work and employment and/or being forced into situations on the grounds of disability in those contexts. This code was applied to situations in which the person with disabilities *lacked choice* due to limited or no adequate information, lack of available options, or because others made decisions for her.

Exclusion: Interviewee is experiencing segregation and isolation on the grounds of disability, including lack of accessibility. Whenever the persons with disabilities were absolutely prevented from participating in any event or activity or absolutely prevented from entering or using the physical environment, the situation was coded as Exclusion. The code Exclusion was also applied to situations that involved *denial of access* to spaces, places, services and programmes.

Discrimination and Inequality: Interviewee is experiencing any *distinction, exclusion or restriction* on the basis of disability denying the effective recognition, enjoyment or exercise of human rights and basic freedoms on an equal basis with others. This code was assigned every time the person with disability experienced a *different treatment* on the basis of his/her disability, either directly or indirectly.

Disrespect of Difference: Being disrespected and/or labelled on the grounds of disability and/or not having disability-related needs properly addressed. This code was applied to situations in which the person with disability was *judged, labelled an/or insulted*, on the basis of certain assumptions that others made about her disability. It was also applied to situations in which *the needs of the person with disabilities (to be heard or the have her disability accommodated for) were not taken into consideration*.

4.2.5 Comparative aspect of the research project

While the system and individual monitoring in Germany and Portugal reveals the substantive effectiveness of national policies, the aim of the present study is also to compare national policy approaches to identify best practice policies both countries can learn from. Comparative, cross-cultural studies are controversial and as Smelser

outlines “most of the critical discourse about [the nature of] comparative variables [within cross-cultural studies] is negative in the sense that critics point out that one or another variable is culture-bound or otherwise inappropriate" (Smelser 1976, 195). Nevertheless, it is also argued that in a globalised world methodological nationalism is insufficient to uncover all aspect of contemporary social phenomena (Beck and Poferl 2010, 20). Furthermore, within contemporary critical disability discourses it is argued that disability rights need to be enforced and implemented locally, but thought about globally (Corker and Shakespeare 2002; Lindqvist 2004). For a cross cultural analysis, however, a comparativeness of units needs to be given (Schmitter 2008). I claim that such a comparativeness of units is provided in the present study.

Certainly Portugal and Germany are two countries that differ in various points: Portugal, for instance, is usually classified as a Southern welfare state in which the family is the primary locus of solidarity and social support (Karamessini 2007; Ferrera 1996). In contrast, Germany is in general classified among the conservative welfare state regimes (Esping-Andersen 1990) with a high level of social protection[38]. Both countries, however, belong to the European Union and both countries have been influenced by supranational legislation, such as the European Employment Equality Framework Directive or the European Disability Strategy 2010-2020 and most prominently by the international disability human rights framework. Comparative data further suggest that in both countries disabled people are in a disadvantaged position when it comes to labour market participation - in both countries, for example, there is an employment gap (United Nations 2012b; Thornton and Lunt 1997). A report on the employment situation of disabled people in Germany conducted in 2009, highlights that the German rehabilitation system is marked by segregate and exclusionary strategies and that sheltered employment is a well-established segment of the disability related labour market (Waldschmidt, Lingnau, and Meinert 2009). Furthermore, in Germany many new policies and programmes offer highly individualised support. In contrast to Germany, in Portugal there has been a notable shift from individual programmes to a more mainstream approach in regards to the

[38] Some authors claim that Germany has made a silent change from a conservative welfare state towards a more universal, Anglo-Saxon welfare state since its implementation of the Hartz IV reform in 2004 (Fuchs 2013).

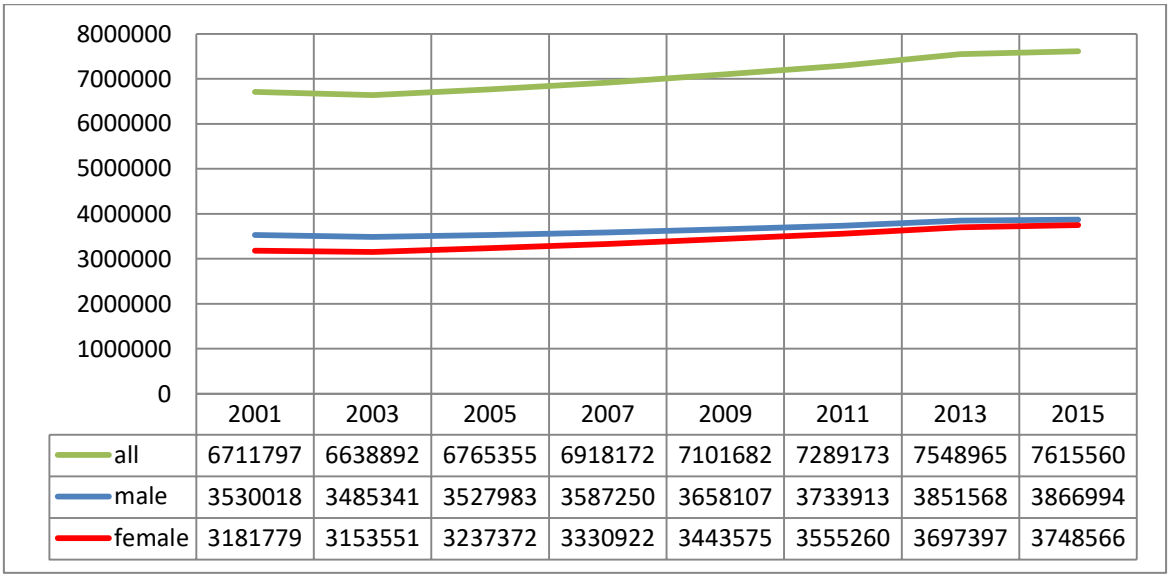
employment policies for people with disabilities. The comparative perspective of the study aims to reveal how the different factors and the recent changes made in light of the international disability human rights framework have impacted disability policies and the de-facto situation of disabled people. The bi-national comparison aims to identify best practice policies both countries can learn from.

In the following three chapters the study results are illustrated: In chapter 5 and chapter 6 it is outlined how national employment legislation for disabled people has historically emerged and how these policies have been influenced by the Convention on the Rights of Persons with Disabilities. Chapter 7 presents the results gathered from the in-depth interviews. All three chapters pave the way for a systematic and comparative analysis and the discussion in chapter 8.

5 Disability employment policies in Germany in light of the Convention on the Rights of Persons with Disabilities[39]

In Germany, the number of disabled people has been rising in recent years. Based on the German Microcensus data[40] there has been an increase of 16 % of people living with a disability between 2005 and 2013. In 2013 the numbers have increased to 12,77 Million (15,8% of the German population) (Bundesministerium für Arbeit und Soziales 2016b, 35). In 2015, about 7.6 Million or 9,3% of the German population have been classified as severely disabled. This marks an increase of more than 900 000 between 2001 and 2015 (see chart below) (Statistisches Bundesamt 2017).

Graph 12: Numbers of Severely Disabled People in Germany



	2001	2003	2005	2007	2009	2011	2013	2015
all	6711797	6638892	6765355	6918172	7101682	7289173	7548965	7615560
male	3530018	3485341	3527983	3587250	3658107	3733913	3851568	3866994
female	3181779	3153551	3237372	3330922	3443575	3555260	3697397	3748566

Source: Destatis 2017.

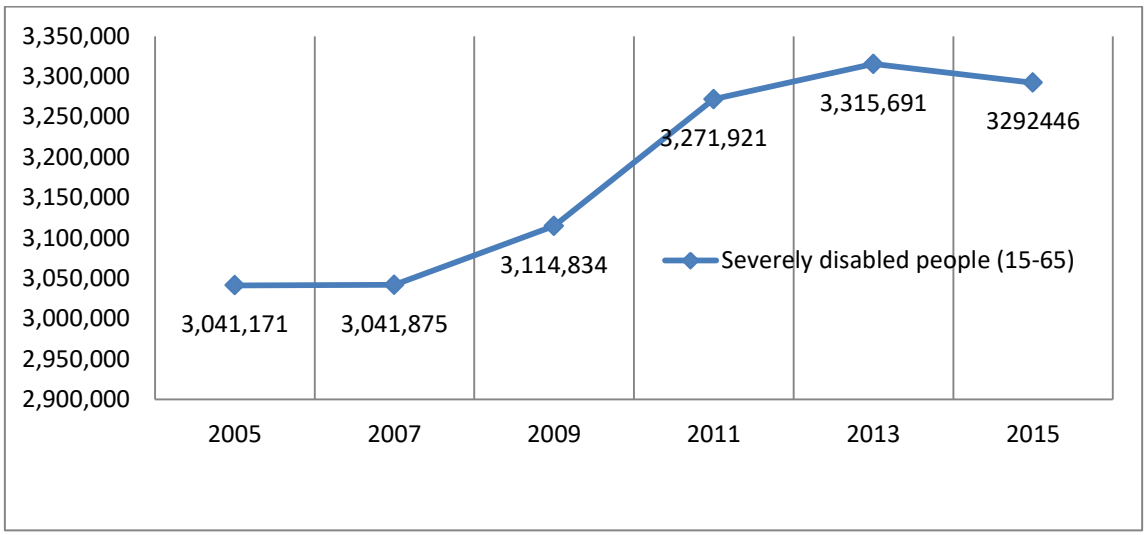
In 2015 more than three quarters of the severely disabled people were aged 55 or older. The numbers indicate that due to the demographic changes in Germany the prevalence of disability is on the rise (Statistisches Bundesamt 2017, 5). However, demographic changes in Germany are only one reason for the increase between 2005 and 2015. The prevalence of disability was also on the rise amongst people aged

[39] The present analysis was completed in 2018 and does not include any updates or amendments made in German laws or policies after that.

[40] The Mikrozensus is a statistical survey in which a percentage of the German private household takes part. The Federal Statistical Office is conducting the survey on an annual basis. However questions on disability are only made every four years. Most recent figures from the Mikrozensus are available of the year 2013.

between 15 and 65 years- people of working age. The chart below shows that also a minor decline occurred between 2013 and 2015, the numbers rose from 3.041.171 in 2005 to 3.292.446 in 2015.

Graph 13: Severely disabled people aged between 15 and 65 years in Germany



Source: Severely disabled statistics 2005-2015, available online at www.destatis.de

In 2015 about 6 % of the German population aged between 15 and 65 years were registered as severely disabled. Within this age bracket, the highest percentage of severely disabled people occurred among people aged between 55 and 65 years. The proportion of severely disabled people also increases with rising age among the unemployed population. However, the proportion of unemployed people with a severe disability aged 55 years or older is below the proportion of severely disabled people in the overall population in the same age group. The fact that the numbers of severely disabled employees have risen the most among employees who are older than 50 (between 2007 and 2015 by 52 %), is an indication that the overall increase of severely disabled people is not only due to demographic changes but might also have socio-political reasons (Statistisches Bundesamt 2017). To be classified as severely disabled enables access to specific measures and policies (see for example Initiative Inclusion, BEM or the special dismissal protection) and thus supports and protects employment. The numbers indicate that to be classified as severely disabled is, in particular for workers aged 55 years or older, a desirable option. An increased awareness about disability in work and employment might have contributed to this development.

Despite existing legislation and an increased awareness, disabled people find themselves in a disadvantaged position in the labour market. In 2016, the unemployment rate of severely disabled people was 12,4%[41] compared to 6,1 % for non-disabled people (Bundesagentur für Arbeit Statistik 2017, 161). Since 2007 the unemployment rate of severely disabled people has decreased by 5 % while the unemployment rate of non-disabled people has decreased by 25 % (Bundesagentur für Arbeit Statistik 2017). The comprehensive Government report on the Participation of Disabled People[42], published in 2013 outlines, in regard to work and employment, that the employment rate of both disabled men and women was 58% compared to 83% of non-disabled men and 75% of non-disabled women (Bundesministerium für Arbeit und Soziales 2013, 130). Furthermore, the participation report of 2016 shows that only 40 % of people with an impairment claim that their earnings are the main source of income, whereas 74% of the overall working age population sustain their living through employment (Bundesministerium für Arbeit und Soziales 2016a, 155). The rising numbers of (severely) disabled people and their disadvantaged position in the German labour market call for social policy responses. The present chapter critically reviews the employment policies and legal framework for disabled people in Germany. It is argued that the historical development of disability policies have an impact on the present system. Therefore a brief overview of the historical development of disability policy in Germany is provided in the first section of this chapter. As the international disability rights framework is becoming the blueprint for recent disability policies, the current status of the CRPD in Germany is outlined in the second part. In the last part of this chapter, present employment and work policies are critically analysed.

5.1 Disability policy in Germany – a long history of segregation and oppression

The first part of this chapter aims to provide a brief historical overview on the development of disability policies in the German context. Whereas there is

[41] 11,7% in West Germany and 15,2% in East Germany

[42] Original title of the English short version reads “Federal Government Report on Participation with regard to the circumstances of persons with impairments”. The report is available online at https://www.bmas.de/SharedDocs/Downloads/DE/PDF-Publikationen/a125-13-e-teilhabebericht-2013-englisch.pdf?__blob=publicationFile [last accessed on 05/03/2017]

comprehensive literature available about recent changes and developments, fewer work is available covering the time of the middle age and 16th century and Absolutism (Fandrey 1990) - a wider scope of research work is covering the development dating back to the end of the 19th century and the early emergence of the social insurance system in Germany (Eghigian 2003; Ziem 1956). The time after World War I, in particular the time of the Nazi regime and the social policy responses towards people with a disability during the Third Reich has been the primary focus of researchers (Klee 1983; Poore 2007; Biesalski 1915; Fandrey 1990; Eghigian 2003; Burleigh 2002; Ziem 1956). Nevertheless, a growing number of research literature is available tracing the social policy responses in the divided Germany after World War II (Fulbrook 2005) and the development after the unification process in 1990 (Poore 2007).

5.1.1 16th century and absolutism

As in other parts of the Western World, the majority of disabled people were socially included and visible in everyday life in Germany prior to the industrial revolution and the division of the private and public sphere. The structure of work offered the possibility for many disabled people to be included in the world of work, even if they were not able to keep up the same rate of production (Metzler 2013, 73; Fandrey 1990, 10; Stiker 2002). Despite this more 'inclusive' world of work, for many disabled people, begging was the only mean to sustain an income within the feudal system of the Middle Ages. During the Enlightenment process a more secular world view became predominant in Germany and ill health was no longer considered to be given by god. As a consequence, begging lost its social acceptance and the first laws were introduced that only permitted a certain group of citizens to continue begging in public spaces. The main criteria to receive such an allowance for begging ("städtisches Bettelzeichen") was the personal "inability to work" (Fandrey 1990, 41).

After the Thirty Years' War (1618 to 1648), begging became the main source of income for 10 to 25 % of the population. Due to the increasing numbers a main goal for policy makers was the punishment of begging and the increase of personal productivity. As a consequence, workhouses ("Arbeits- und Zuchthaus") emerged in which disabled people were sheltered amongst other socially excluded groups such as criminals (Fandrey 1990, 50–59). Whereas later policies distinguished between

different groups of disabled people, such as war veterans and people with a congenital impairment, there was no such distinction in the 17th century (Fandrey 1990, 88).

5.1.2 The Social Question and the emergence of the social insurance system

With the rise of the industrial society, individual work efficiency gained importance and many disabled people were left behind. At the same time, due to the emergence of the private and public spheres, it was no longer possible for many disabled people to be looked after and cared for in their family (Fandrey 1990). At the end of the 19th century, with the emergence of the "Social Question" ("Soziale Frage"), an increasing number of working poor demanded new policy approaches and challenged the existing social system. In response, the conservative Reich Chancellor Otto von Bismarck (1871-90) addressed the social uprising by introducing a comprehensive social insurance regime (Eghigian 2003; Fandrey 1990). As Eghigian outlines the aim of the heuristic insurance system was to:

> "replace social revolution with social reform by maintaining economic productivity and integrating workers into society by ensuring some minimum existence. This served to institutionalize some of the most basic tensions in modern capitalist society" (Eghigian 2003, 281).

The three original branches of the German social insurance system were:

- health insurance (1883)
- accident insurance (1884)[43]
- invalidity and old-age pension (1891)

Within the insurance system[44], an epistemology of disability was developed that privileged the visible, the observable, and the scientifically verifiable. The insurance

[43] The accident insurance covered only wage labourers earning no more than 2000 marks a year. Beneficiaries were mainly male workers. Female occupations and industries were excluded from the insurance system (Eghigian 2003, 87).

[44] From the early stages the social security system was subject to criticism. As Hartz claims, whereas the social insurance system was introduced to promote personal autonomy, civic peace, and social security, it created a system in which individual property was replaced with a legal claim to

boards necessarily called personal experience and expression into question, inherently delegitimizing the laments of the injured (Eghigian 2003, 83–84). As Eghigian outlines the rise of social insurance

> "represents an important chapter in the history of the secularization of the body, health, and illness. German social insurance gave birth to "disability" as the twentieth century would come to know it" (Eghigian 2003, 115).

For people who become injured in the work place, the social insurance system improved their economic situation, as under the accident and invalidity pension schemes they became entitled to social benefits to cover income losses. The invalidity pension, however, remained low and disabled people who acquired their disability outside of the workplace or had a congenital impairment and who were unable to participate in the labour market were not covered[45]. The growing division of the private and public sphere further increased the demand for disability-specific institutions. In 1914, Herman Simon, a director of a mental hospital in Warstein (Westfalen) discovered that a regular daily activity improved the mental health of his inmates - the early concepts of "work therapy" were born (Burleigh 2002, 45; Fandrey 1990, 143). Thenceforward occupational daily activities became an important part of the daily routine in many German institutions for disabled people.

5.1.3 The beginning of the 20th century – from care for war cripples to a comprehensive rehabilitation system

At the end of the First World War (1914-1918) many healthy young men from diverse socioeconomic backgrounds found themselves injured and disabled. Consequently the provision for disabled people could no longer be viewed as primarily a charitable endeavour for the poor but required a new social policy response (Poore 2007; Fandrey 1990; Eghigian 2003). The group of injured war veterans seemed to have an unquestionably legitimate claim to the moral and financial support necessary

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entitlement. This led to a system in which the meaning of labour diminished and in which personal responsibility was replaced with dishonesty, and ingratitude. Hartz further outlines that the bureaucratic system itself is a social burden due to its high costs (Hartz 1928).

[45] Only with the introduction of "the severely disabled people act" in 1974 the cause of disability was no longer important for the legal entitlement to specific rights and support measures.

for their reintegrating into society (Poore 2007, 3; Eckertz 2009, 432). In Germany, the Unions had claimed for an employment quota to support war veterans ("Kriegsinvaliden") since 1917. The government (Reichstag) introduced such an employment quota of 2 % in 1918 for all employers who employed more than 50 workers. Reintegration into work became the main policy aim in regard to disabled people. This aim was strengthened by a rehabilitation system which had developed during and after World War I and was at that time one of the most advanced and best-organized in the world with its mixture of church and state-sponsored institutions and hospitals (Poore 2007, 9). Rehabilitation professionals who had previously mainly worked with "crippled children" began to apply their expertise to the needs of disabled war veterans. Disabled soldiers were obliged to secure their own economic future and to contribute to the economic prosperity of the nation - they had a patriotic obligation to do so (J. Andersen and Perry 2014, 238; Ziem 1956, 29). Konrad Biesalski is considered as one of the main advocates who supported and promoted the reintegration of injured war veterans into work. His booklet "The Care of War Cripples: A word of Enlightenment for Consolation and Warning"[46] aims to convince the disabled soldier (and any other (physically) disabled person) as well as the general public that full working capacity can be restored through rehabilitation measures. He claimed that the numerous war cripples have the duty to merge into the masses of workers and become taxpayers rather than charity recipients (Biesalski 1915, 34). Poore outlines the contradictions of such an approach:

> "the most problematic aspect of theories such as those of Biesalski […] was the overbearing emphasis they placed on work in connection with their construction of an abnormal psychology of disabled people. Partly to legitimate their own field, these experts insisted that most disabled people could learn or relearn to work – a guiding principle that of course had many positive, empowering aspects. They applied this principle in an extremely inflexible manner, however, viewing those who truly could not work as having weak wills or other negative psychological characteristics. Furthermore, the result of this approach for those who truly could

[46] Authors translation into English. Original title: „Kriegskrüppelfürsorge: Ein Aufklärungswort zum Troste und zur Mahnung"

not work or care for themselves – the most severely physically disabled people and the majority of those with mental illnesses or cognitive disabilities – was the conclusion that they should be consigned to the margins of society and frequently to institutions" (Poore 2007, 50).

Although most of the treatment measures, rehabilitation practices and therapies addressed precisely disabled soldiers, they were extended to disabled civilians. In 1920, the passing of the *Law for the Severely Injured* extended the rehabilitation system to people who gained their impairments at work. The extension of the law granted thousands of disabled Germans access to a modern rehabilitation system - something that was not available prior to World War I (J. Andersen and Perry 2014, 246). Improvements in prosthetic technologies, along with the shortage of workers created a wide range of occupations for persons with functional impairments. As Poore claims this development and the increasing emphasis on efficiency and modern production methods transformed interrelationships between human bodies and machines and had both liberating and oppressive aspects that were constant sources of political and cultural tensions (Poore 2007, 3). The final goal was to repair and return the permanently injured body to the workforce, rather than to simply compensate its 'owner' with a monetary pension. Many people became resentful of veterans' demands for financial benefits and they stressed instead their patriotic obligation to heal their injured body and return to the workforce (J. Andersen and Perry 2014; Poore 2007). At the same time, the new emphasis on rehabilitation threatened the employment of many disabled people who had been able to obtain employment during the war due to a lack of able-bodied workers (Fandrey 1990, 160). To address this matter and protect these workers a *prohibition for dismissal* ("Kündigungsverbot") for severely disabled people was introduced in 1919. However the *Law for the Severely Injured* (Schwerbeschädigtengesetz) of 1920, weakened the prohibition and introduced instead a *protection against dismissal* ("Kündigungsschutz") which is still in place today. While under the prohibition for dismissal employers were unable to dismiss a severely disabled employee, the new legislation weakened the protection. Until today every dismissal of a severely disabled person needs to be approved by the Integration Offices. The authorities prove if the dismissal is justified

and/or if there are support measures in place that can protect the employment. Only when the dismissal is considered to be justified by the Integration Offices it becomes lawful.

5.1.4 1933 - 1945 - Euthanasia and the ability to work

The social policy agenda changed dramatically when in the years that proceeded the Second World War, social Darwinism and eugenic world views became dominant in Germany (Burleigh 2002; Fandrey 1990; Klee 1983). The writing "Die Freigabe der Vernichtung lebensunwertes Lebens" ("Permission for the Destruction of Life Unworthy of Living") by Prof. Karl Binding and Dr. Alfred Hoche was one of the most influential publications regarding the emerging debates about euthanasia[47]. The authors (Binding and Hoche 1920) question[48] if there is human life that no longer inherits the social and individual value of being lived, as the human being has lost all its entitlements and rights. Arguing from both a political perspective (Binding) and a medical perspective (Hoche) the publication concludes that there is such human life, which is unworthy of being lived, in favour of the higher value of society. In particular people with a mental disability and people suffering from an incurable illness are perceived as unable of living lives worth living in the first place and as a burden to society in the second place. Therefore the murdering of such groups can be seen as a social duty to sustain the German race (Klee 1983). Releasing people from their suffering is described as an *act of mercy* (Binding and Hoche 1920). As a consequence of such ideas, institutions for disabled people ("Pflege und Heilanstalten") were increasingly subject to financial cut backs and forced sterilisation became lawful in 1934 (Fandrey 1990, 185; Burleigh 2002, 39). As Klee outlined prior to the sterilisation laws, unlawful sterilisation of disabled people was already a common practice in many institutions (Klee 1983). Such policy measures reached rock bottom in October 1939 when Adolf Hitler signed an

[47] Until the end of the 19th century the term "Euthanasia" had its original meaning in "easy death" from the Greek "eu" "well" and "thanatos" "death". At the end of the 19th century, however, Adolf Jost proclaimed not only the »right to die" but also the right to kill somebody who is an unreasonable burden to society (Burleigh 2002, 22–23). The Oxford dictionary defines Euthanasia as "The painless killing of a patient suffering from an incurable and painful disease or in an irreversible coma".

[48] Original question "Gibt es Menschenleben, die so stark die Eigenschaft des Rechtsgutes eingebüßt haben, daß ihre Fortdauer für die Lebensträger wie für die Gesellschaft dauernd allen Wert verloren hat?"(Binding and Hoche 1920, 27).

authorisation to Euthanasia which was dated back to 01st September 1939 (beginning of the Second World War). Under the authorisation, disabled people became subject to Euthanasia instead of sterilisation practices. The individual ability to work ("Arbeitsfähigkeit") became the primary criteria that determined if a disabled person was killed or was left alive. In the "Tötungsaktion" "T4" (Tiergartenstr. 4) between 80 000 and 100 000 disabled people were killed until 1941. More disabled people were killed afterwards in concentration camps and in special programmes that considered the lives of disabled children "unworthy" (Fandrey 1990, 193–94; Klee 1983). As Klee outlines the implementation of the killings was organised undercover. Code names served to hide the cruelties from the public. The increasing amounts of disabled people being killed provoked resistance in the public first, in particular amongst family members and the staff occupied in the institutions. However, the murdering continued in a muted second phase – the so-called "wild" euthanasia phase (Eyre 2008). Euthanasia continued in the form of medical overdoses and food deprivations (Klee 1983, 430; Burleigh 2002, 273). The main argument that supported euthanasia practices was that a mentally ill person occupies the bed of a war veteran. Such arguments silenced many opponents (Klee 1983, 175). A new identification sheet ("Meldebogen"), introduced in 1940, redefined the selection criteria. People with disabilities that had a higher workability were often spared from the killing (Klee 1983, 177; Poore 2007, 88; Burleigh 2002, 162).

5.1.5 Disability in a defeated nation[49]

Although people with disabilities have been amongst the groups on whom the national socialists attempted to enforce their distinctions between the sick and the healthy with the ultimate goal of eliminating the sick from the body of the German nation, the rights of people with disabilities have not found much response in the German post-war society (Poore 2007). As Eyre outlines the post-war period was marked by an uncomfortable silence in respect to the disabled population's treatment during the NS regime (Eyre 2008, 58). As Germany was divided into the Western Federal Republic of Germany (FRG) and the Eastern socialist German Democratic

[49] For a comprehensive analysis of the post war years, see (Poore 2007, 99; 152–307).

Republic (GDR) from 1949 until 1990, German social policy discourses need to be considered in the two social contexts separately during these years (Fulbrook 2005; Poore 2007). In both parts of Germany, however, disabled veterans had not the same heroic status as after World War I. In the FRG, as well as in the GDR the occupying allies (America, Great Britain and France in the FRG and the Soviet Union in the GDR) aimed to prevent the encouragement of further militaristic sentiments and therefore pension schemes for disabled veterans were restricted (Ziem 1956, 46; Poore 2007, 171). Despite these similarities, there were also differences in the way disability policy evolved in the two parts of Germany. The differences are mainly grounded in the opposing political frameworks of West and East Germany.

5.1.5.1 Federal Republic of Germany (West Germany)

Due to the lack of a democratic acknowledgement of people with disabilities as equal citizens, disability became more or less a taboo subject in the early years of the Federal Republic of Germany (Poore 2007; Eyre 2008). Disability discourses in the Federal Republic of Germany continued to be mainly influenced by a charity approach. A rights approach and/or a political consciousness have long been undervalued (Bielefeldt 2009; Graumann 2009; Eyre 2008). After the Second World War, the existing pre-war law for the Severely Injured of 1920/23 was no longer sufficient to deal with the increasing numbers of disabled war veterans and injured workers. The law was renewed in 1953 extending the group of people covered[50] and the obligations of employers (Ziem 1956, 61). Disability was defined in regard to the individual ability to work. A person not being able to achieve at least 50 % of working capacity was considered disabled (Bundestag 1953, §1). Due to the economic boom ("Wirtschaftswunder") an increasing number of disabled workers could be integrated in the workforce. However, the majority of disabled people were cared for in medical and educational institutions - segregated from the general public. The tendency to segregate people with impairments has maintained the ascendancy in Germany (Eyre 2008, 59).

[50] Besides injured war veterans and people who gained their impairments at work, the new law also applied to blind or partially visually impaired people who depended on ongoing support (Ziem 1956).

In 1974, the “Severely Injured People Act” (“Schwere***beschädigten***recht”) was reformed and renamed “Severely Disabled People Act” (“Schwerbe***behinderten***gesetz”). The Severely Disabled People Act has formed the basis of the German disability policy ever since. For the first time in the German context, disability policies were extended to cover all severely disabled people, whatever the origin or nature of their disability (Waddington 1995, 230). The new law modernised amongst other things the quota system and strengthened the role of an ombudsman for disabled people. The Severely Disabled People Act of 1974 also introduced sheltered workshops. In the FRG, a broad rehabilitation system of special institutions emerged. Rehabilitation became the dominant paradigm and within the rehabilitation paradigm, work and the long-term integration in work and employment became a core goal supported by physicians, policy makers and researchers. However, this goal was mainly achieved through the rising number of admissions to segregated workshops. The predominance of the medical model of disability led to the rise of special institutions which often specialised on specific kinds of disabilities. In Germany, the socialisation of a child born with a disability often took place in segregated environments, starting with the attendance in a special kindergarten, and being continued with the education in special schools and the admission to a sheltered workshop. Furthermore, people with disabilities who were not able to live independently and who needed (extensive) care, were often excluded in special care facilities. Whereas disabled people in the Federal Republic of Germany often gained a high degree of material security, they were segregated in institutions and excluded from mainstream social structures (Fandrey 1990; Poore 2007). Poore outlines that, due to long time segregation and social exclusion, the UN Year of People with Disabilities (1981) was opposed by some disabled activists in the FRG, merely because they had been excluded from the organisation and preparation of the year. Such a hostile attitude of disabled people against official events that aim to raise awareness and promote rights could be seen as a sign of the power of the non-disabled experts (Poore 2007).

5.1.5.2 Disability in the German Democratic Republic (East Germany)

In contrast to the FRG, the German Democratic Republic was influenced by socialist theory and practice. The image of the ideal citizen was portrayed as a strong, healthy worker who can achieve economic justice for all through his/her individual productivity in socialist labour processes (Barsch 2008, 4). Based on the materialist perspective within the socialist worldview, all human beings were seen as fundamentally equal and largely shaped by their environment. Whereas it could be said that during the Third Reich the humane vision of socialism, "all for one", was displaced by the nationalistic, racially determined slogan "one for all" (Poore 2007, 248), Poore stresses that these two concepts from socialist theory are important background information to discuss policies and attitudes toward disabled people in the GDR. In addition to the concept of the "socialist personality", the concept of "performance" was crucial. The concept of performance was derived from Marx's reflections in *The Critique of the Gotha Program (1875)* on the analysis on how the proceeds of labour could be distributed fairly in the future cooperative society. Consequently, GDR policymakers considered it necessary to compensate workers according to their performance in order to motivate them to work up to their limits. They were assuming that all members of the socialist society had an equal relationship to the means of production and they were also assuming a synchronicity of interests between the collective and the individual. For disabled people, the predominant emphasis on performance had contradictory tendencies: On the one hand, the constant emphasis on the individual performance in terms of work productivity resulted in broad efforts to rehabilitate people with disabilities and to integrate them in the labour force. However, on the other hand, there was a constant pressure to perform, which also had an exclusionary effect on many disabled people who needed extra care and support and who were truly not able to work in the existing industries (Poore 2007, 249–50). Nevertheless, living in a socialist society disabled people - as all other citizens - had the right to work guaranteed in the constitution. This was fundamentally different from the capitalist Western part of Germany. Rehabilitation measures in the GDR were divided in four different sections: the medical, the educational, the vocational, and the social rehabilitation system (Hauser et al. 1996, 291–92). The system of a planned economy limited the individual choices of trades and professions for both disabled and non-disabled workers (Poore

2007, 259–60). Due to a lack of economic resources, not all rehabilitation aims could be achieved and the less productive members of society were often housed in inappropriate aged care facilities or special institutions (Hauser et al. 1996, 292; Fulbrook 2005). The absence of any discernible social and political lobbies for people with disabilities prevented a social push towards self-determination and participation until the end of the GDR (Barsch 2008, 3; Eyre 2008).

After the reunification process in 1990, the Western system of market economy was imposed on the former Eastern parts of Germany. As a consequence enterprises were privatised. Many disabled East Germans, despite experiencing a higher standard of living, had poorer outcomes in terms of participation in work and employment after the reunification (Poore 2007, 271; Hauser et al. 1996, 293–96). The changes and developments that have been made since the reunification process and that shape the present system will be outlined in the following paragraph. Prior to the analysis of recent and present disability (employment) policies, the status of the CRPD and the German disability human rights system will be illustrated in more detail, as the implementation of the international human rights framework has been influencing recent policy responses in the field of disability.

5.2 UN Convention status in Germany

The Convention on the Rights of Persons with Disabilities and its Optional Protocol was signed by the German government on 30th March 2007 and ratified on 24th February 2009. The Convention came into force on 26th March 2009. Germany did not present any declarations, reservations or objections in relation to the UN CRPD and its Optional Protocol. In the German context, however, contradictions have emerged in regard to the official German translation. Article 50 of the CRPD states that the Arabic, Chinese, English, French, Russian and Spanish texts of the present Convention shall be equally authentic and therefore these texts represent the initial purpose of the Convention. Several passages of the German translation have been subject to criticism by disability organisations and advocates[51]. Due to the widespread criticism a *shadow translation* has been published by the NETZWERK ARTIKEL 3 e.V. in 2008[52].

[51] For example, the English phrase “independence” and “live independently” has been translated with

Overall, the negotiation process of the CRPD has been accompanied by the ongoing debate about the extent to which the CRPD is already implemented in German legislation. Whereas one group of researchers argue that the CRPD has nothing new to offer as the German system already treats its disabled citizens as rights bearers and not as objects of charity[53] (Luthe 2016), other scholars claim that the German system is still marked by segregation and a paternalistic welfare system and therefore is not in line with the human rights framework (Degener 2009; Graumann 2009). In regard to work and employment, the second group in particular condemns the widespread system of sheltered employment and special education system. Furthermore the English term "inclusive" and "inclusion" have been translated to "integrative" and "Integration" in the official German translation. Scholars argue that the German translation is more compatible with the concept of "integration"[54]. While integration usually means inserting the person in existing systems/structures without changing much of the context but expecting the person to adapt, inclusion means that existing structures need to change to accommodate the needs and differences of the people who are included (Wunder 2010). Consequently the German translation does not reflect the original spirit of the Convention which emphasises on an inclusive labour market (Schulte 2016, 25–26; Degener 2009; Trenk-Hinterberger 2016, 108). Following the debate, the German term "Inklusion" is nowadays widespread and used in policy discourses that address the inclusion of disabled people in work and employment and in education (see for example the "National Action Plan", or the "Initiative Inklusion"). The ratification process has raised awareness about disability among policy makers and the wider public. On December, 23rd, 2016 a new disability law, the

the term "Unabhängigkeit" and "unabhängiges Leben" rather than with the more applicable term "Selbstbestimmung" und "selbstbestimmt leben" (Schulte 2016, 25).

[52] The shadow translations is available online at http://www.netzwerk-artikel-3.de/index.php/vereinte-nationen [Date accessed 04/03/2017]. In the meantime, Austria has published a revised official German translation for Austria (16/08/2016). The document is available online at https://www.ris.bka.gv.at/eli/bgbl/III/2016/105 [date accessed 10/11/2017].

[53] In addition it is often argued that the Convention is not offering clear instructions and therefore has no meaning for national law (Luthe 2016).

[54] There is a debate amongst German scholars in regard to the proper translation of the term inclusion. Whereas one group argues that the German concept of "integration" is equal to the concept of "inclusion" in the way the CRPD promotes it (Luthe 2016) opponents of this understanding argue that the German concept of Integration is not equivalent to the English term inclusion and therefore the German translation is not in line with the human rights approach (Degener 2006).

"Bundesteilhabegesetz - a law for strengthening the participation and self-determination of people with disabilities[55], was signed which aims to further strengthen the CRPD in the German system. The new law will come into force in four stages from 2017 until 2023. The present study will refer to this new law, whenever it involves changes made in relation to the existing legislation.

The Federal Ministry of Labour and Social Affairs (BMAS) is the focal point for the implementation of the Convention. To systematically advance the implementation of the UN Convention, the Federal Ministry of Labour and Social Affairs has implemented a National Action Plan in August 2011 with a time horizon of ten years. The aim of the Action Plan is to create an inclusive society. Whereas the Action Plan is described as a "motor for change" consisting of more than 200 schemes (Federal Ministry of Labour and Social Affairs 2011, 3) – it is not a set of laws. The National Action Plan is structured according to twelve fields of action and seven cross-sectional topics[56]. Alongside with others[57], work and employment is a core area for action. It is a core endeavour of the Federal Government to develop an inclusive world of work (Federal Ministry of Labour and Social Affairs 2011, 6). The Federal Government has provided 100 million for the "Initiative Inklusion" programme that aims to ensure greater employment for persons with severe disabilities. The programme targets on the one side young adults and students that want to complete a training in the open labour market and on the other side older persons with a severe disability (50 years and older) who are unemployed or who are looking for work. A main emphasis of the programme is to inform school leavers about their professional perspectives and to support vocational training in the open labour market (Bundesministerium für Arbeit und Soziales 2011, 15).

[55] Gesetz zur Stärkung der Teilhabe und Selbstbestimmung von Menschen mit Behinderungen (Bundesteilhabegesetz - BTHG)

[56] The seven cross-sectional topics are (1) need of assistive services, (2) accessibility, (3) gender mainstreaming, (4) Equality, (5) migration, (6) self-determined living and (7) diversity of disability. These topics are applied to all fields of action (Federal Ministry of Labour and Social Affairs 2011).

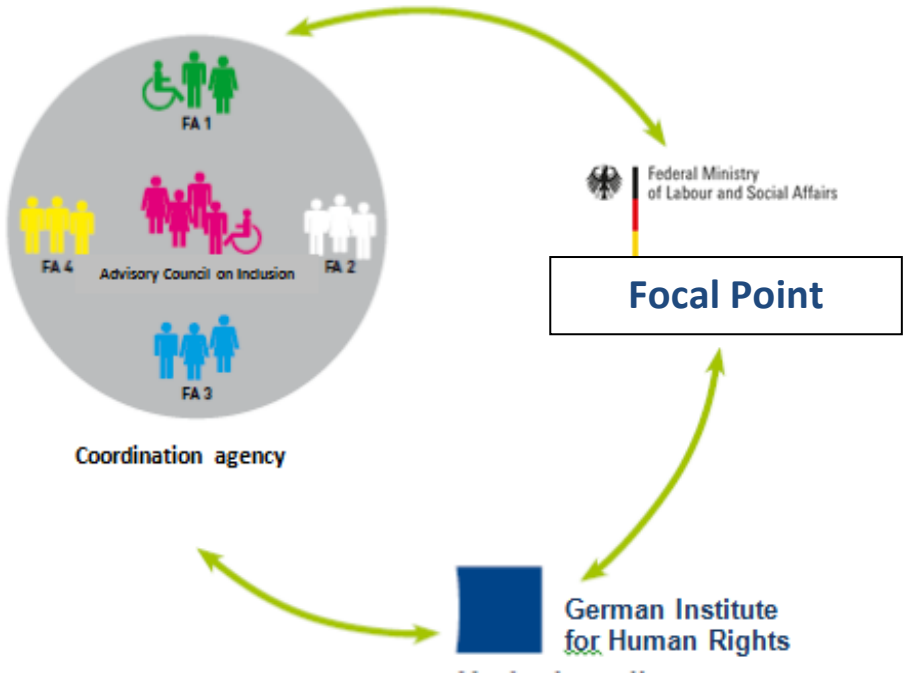
[57] Areas of action: (1) work and employment, (2) education, (3) prevention, rehabilitation, health and care, (4) children, youth, families and relationships (5) women, (6) the elderly, (7) build and living environment, (8) mobility, (9) culture and leisure, (10) social and political participation, (11) individual rights, (12) international cooperation.

Since 2008, the State Coordination Agency[58] is located at the office of the Federal Government Commissioner for Matters relating to Disabled Persons. The task of the State Coordination Agency is to facilitate the implementation of the various measures which have been developed at the State Point of Contact (Focal Point). Furthermore, the State Coordination Agency shall facilitate the integration of people with disabilities and the civil society in the implementation process. In order to fulfil this task, the state coordination agency has established an Advisory Council on Inclusion. The Advisory Council on Inclusion is supported by four special committees each addressing a different thematic area: (1) health, care, prevention, and rehabilitation, (2) Autonomy and protection rights, women, partnership and family, bioethics, (3) employment and education, (4) mobility, built environment, living, leisure, social participation, information and communication. The work of the Advisory Council on Inclusion and the special committees is coordinated by a secretariat located at the office of the Federal Government Commissioner (Beauftragte der Bundesregierung für die Belange von Menschen mit Behinderungen, n.d.).

The CRPD stipulates in Article 33 paragraph 2 that the State Parties shall maintain an independent mechanism besides the focal point and the public coordination mechanism (Monitoring Mechanism). For this purpose the German Parliament (Bundestag) and the Federal Council (Bundesrat) designated in 2008 the German Institute for Human Rights (DIMR) as the independent mechanism and commissioned it to establish a monitoring mechanism whose tasks would be *inter alia* to come up with recommendations and proposals regarding the implementation of the Convention as well as the counselling of the Federal Government, the German Parliament or other institutions on matters covered by the Convention. Figure 4 shows how the three monitoring bodies work together:

[58] For more information see http://www.behindertenbeauftragte.de/DE/Koordinierungsstelle/Koordinierungsstelle_node.html [date of access 07/10/2017]

Figure 4: The three monitoring bodies in Germany



Source. Beauftragter der Bundesregierung für Menschen behinderter Menschen, Berlin

The first state party report for Germany was due on 24th March 2011 and was submitted on 19th September 2011[59]. In regard to work and employment the report highlights the various existing measures and the schemes undertaken under the National Action Plan. On 14th April 2014 the list of issues in relation to the initial report of Germany was delivered by the Committee on the Rights of Persons with Disabilities. The Committee put the main emphasis on the matter of sheltered employment and the raising numbers of disabled people working in sheltered workshops. Germany responded to the list of issues (29th August 2014) by arguing that the increasing numbers of people in sheltered workshops is not caused by a rise in the admission numbers but by an increase in workshop "manpower resources". In other words, more and more people are able to stay in sheltered workshops until they reach the retirement age and therefore there are less drop outs (Committee on the Rights of Persons with Disabilities 2015b, 19). In its concluding observations (17th April 2015) on the initial report of Germany the Committee was still concerned about the segregation

[59] An initial shadow report was submitted by the BRK-Allianz on 11th December 2013 (BRK-Allianz 2013).

in the labour market. It recommended that the State Party provides regulations that effectively create an inclusive labour market in accordance with the Convention by:

(a) Creating employment opportunities in accessible workplaces, in line with the general comment No. 2 of the Committee, in particular for women with disabilities;

(b) Phasing out sheltered workshops through immediately enforceable exit strategies and timelines and incentives for public and private employment in the mainstream labour market;

(c) Ensuring that persons with disabilities do not face any reduction in social protection and pension insurance currently tied to sheltered workshops;

(d) Collecting data on the accessibility of workplaces in the open labour market (CRPD 2015, 8–9).

In the meantime, further parallel reports have been submitted by the independent mechanism and civil organisations[60]. The information on the parallel reports is included in the following analysis.

5.3 Employment policies and the legal framework for people with disabilities in Germany

As outlined above, with the reunification process most of the Western system was imposed on the former German Democratic Republic (GDR), including the Law for Severely Disabled People. Despite persistent differences between East and West Germany, in particular in respect to the labour market[61], disability policies have been created on a national level for both parts since the reunification. Nevertheless, the

[60] An overview, including all shadow reporting, including the reporting for sessions and in regard to the List of issues is available online at http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Countries.aspx?CountryCode=DEU&Lang=EN [date of access 7/04/2017]

[61] The overall unemployment rate in East Germany remains higher than in West Germany; 7,4% compared to 5,3% in August 2017. Statistical data is available online at https://statistik.arbeitsagentur.de/Navigation/Statistik/Statistik-nach-Regionen/Politische-Gebietsstruktur/Ost-West-Nav.html [date of access 08 /10/2017]

present analysis will refer to differences between West[62] and East Germany[63], whenever there is relevant data available. Considering that Germany is a Federal State, it needs to be acknowledged that the implementation of measures and programmes vary from region to region. In addition, measures that are well established in one part of Germany are not enforced in other parts of the country; the support provided also highly depends on the region disabled people live in (Doose 2012; Diakonie Württemberg 2015; Kardorff and Ohlbrecht 2013). As the current analysis aims to present an overall picture about the policies and programmes that are available on a national scale, no specification between federal states will be made.

The first policy change after the reunification occurred in 2001, when the amendment of the Severely Disabled People Act took place. In order to standardise the various existing regulations and policies and to include the discrimination prohibition enshrined in Article 3 of the German Constitution, a new rehabilitation law - the Social Code Book No. 9 (SGB IX) - was introduced. Until 2018 the SGB IX consisted of two parts. The recently introduced BTHG has amended the SGB IX and extends it to three parts; Part one regulates rehabilitation benefits, part two includes integration supports and part three consists of various provisions for the employment of severely disabled people. Part three (until 2018 part two of the former SGB IX) is replacing the former Severely Disabled People Act of 1974. In regard to Article 27, the most relevant legislation is enshrined in the Social Code Book III, chapter 7, "Promotion of the participation of disabled people in the world of work"[64], and SGB IX, in particular part three (Law for the Severely Disabled).

The Law for the Severely Disabled only covers disabled persons whose degree of disability is at least 50 and who are therefore classified as severely disabled. According

[62] West Germany refers to the so-called "old states", namely Baden-Württemberg, Bavaria, Bremen, Hamburg, Hesse, Lower Saxony, North Rhine-Westphalia, Rhineland-Palatinate, Saarland and Schleswig-Holstein.

[63] East Germany refers to the so-called "new states" of Germany, namely Brandenburg, Mecklenburg-Vorpommern, Saxony, Saxony-Anhalt and Thuringia. As the state of Berlin was divided prior to the reunification process, it neither belongs to the new nor the old states. However, for statistical purpose the state of Berlin usually is considered amongst the group of Eastern German states.

[64] Förderung der Teilhabe behinderter Menschen am Arbeitsleben

to § 2 SGB IX[65], persons are disabled if their physical functions, mental capacities or psychological health are highly likely to deviate for more than six months, from the condition which is considered typical for the respective age and whose participation in the life of society is therefore restricted (Degener 2006). The effect of the functional impairment is labelled *degree of disability* (GdB). The GdB is measured in units of 10 on a scale from 20 to 100. People with a degree of disability of at least 50 are recognized as people with *severe disabilities* in the terms of the law[66]. The degree of disability is determined according to a list of specific impairments and diseases and according to guidelines prepared by a group of medical and legal experts ("Versorgungsmedizin-Verordnung") (Degener 2006; Thomann 2012, 6). The table below shows an excerpt of the official guideline (Bundesministerium für Arbeit und Soziales 2015).

Table 4: German list of specific impairments and diseases

Impairment		**GdB**
Loss of one thumb		25
Loss of both thumbs		40
Loss of four Fingers	Including the thumb	50
	Not including the thumb	40
Loss of five fingers on one hand		50
Loss of all 10 fingers		100

Source: VersMedV (Bundesministerium für Arbeit und Soziales 2015, 116)

In regard to the legal definition of disability the CRPD Committee stated in its concluding observations on the initial report of Germany that "both the federal Government and the Länder revise the legal definition of disability in laws and policies with a view to harmonising it with the general principles and provisions in the

[65] Already in 1986, the classification of disability was modified: Work capacity was no longer the benchmark, but the degree to which an individual condition deviates from the normal condition of other people at the same age.

[66] People with a degree of disability between 30 and 50 can be treated as severely disabled if their employment might be at risk without the severely disabled status. In Germany this is called "Gleichstellung" [Equalisation].

Convention, particularly in matters relating to non-discrimination and full transition to a human rights-based model" (Committee on the Rights of Persons with Disabilities 2015a, 2). Moreover, the differentiation between disabled and severely disabled people creates a gap in German disability policy and has been subject to widespread criticism. It is argued that many employment policies only address severely disabled people and therefore disabled people who are not classified as severely disabled find themselves in a disadvantaged position (Ritz 2011, 426; Deinert and Neumann 2009; Autistic Minority International and ESH 2014; Bundesministerium für Arbeit und Soziales 2014b, 437–40; Welti 2014, 18).

Considering the data on the employment situation of disabled people, the distinction between severely and non- severely disabled people serves as a further barrier. Most of the available information, including statistical data, only covers severely disabled people. The Statistic on Severely Disabled People (Statistik der schwerbehinderten Menschen)[67] for example, is published every two years (since 1985) and includes only data on people with a severe disability. The annual report on the German employment market outlines the annual budget that has been spent for the various employment policies and it includes data on the employment situation of severely disabled people. As outlined above, the unemployment rate of severely disabled people remains more than double as high as the unemployment rate of non-disabled persons. In 2016 the unemployment rate of severely disabled people was 12,4%[68] compared to 6,1 % for non-disabled people (Bundesagentur für Arbeit 2017, 161)[69]. Furthermore, the data reveals that 57,4 % of the unemployed with a severe disability had a vocational degree, compared to 49,6 % of the overall unemployed. In 2016, severely disabled people were on average 86 weeks unemployed compared to an average of 70 weeks in the case of their non-disabled counterparts. Nearly half of the severely disabled unemployed (45,8 %) belong to the group of the long-term

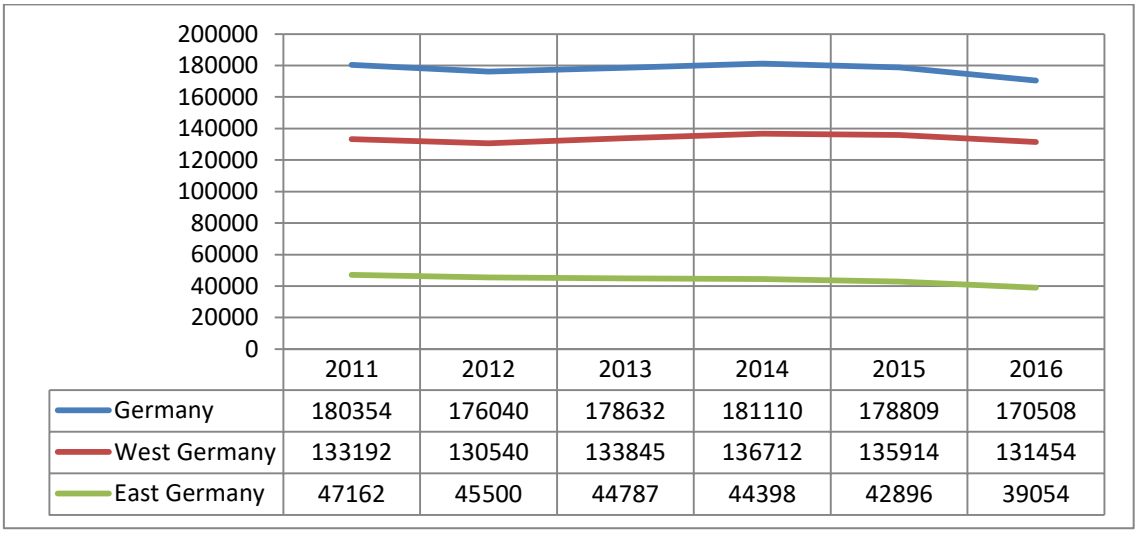
[67] The last report covers the figures of December 2015. The numbers are available online at https://www.destatis.de/DE/ZahlenFakten/GesellschaftStaat/Gesundheit/Behinderte/BehinderteMenschen.html [data of access, 08/10/2017]

[68] 11,7% in West Germany and 15,2% in East Germany

[69] In contrast to many other European countries, the overall unemployment rate of the general population in Germany has decreased during the last years.

unemployed, which means they have been unemployed for more than a year (§ 18 SGB III) (Bundesagentur für Arbeit 2017a, Bundesagentur für Arbeit 2017b). Nevertheless, the number of severely disabled people, registered with the employment agency, has decreased from 180.354 in 2011 to a total number of 170.508 in 2016 (Bundesagentur für Arbeit 2017, 161). The decrease has been higher in East than in West Germany (see chart below).

Graph 14: Unemployment numbers of people with a severe disability, Germany



	2011	2012	2013	2014	2015	2016
Germany	180354	176040	178632	181110	178809	170508
West Germany	133192	130540	133845	136712	135914	131454
East Germany	47162	45500	44787	44398	42896	39054

Source: Bundesagentur für Arbeit 2017

Article 27 of the CRPD requires States Parties to "recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation" (CRPD, Article 27, sentence 1). According to Article 27, these steps include inter alia to prohibit *discrimination* on the ground of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions (CRPD, Article 27, (a)).

Non-discrimination in employment

In the German context, discrimination on the ground of disability is prohibited through the Constitution (GG). The equality clause (§3 GG) of the Constitution was extended in 1994 by a second sentence, and nowadays reads „No person shall be favoured or disfavoured because of sex, descent, race, language, homeland and origin, faith, or religious or political opinions. *No person shall be disadvantaged because of disability"*. In addition to the Constitution, the Act of Equalisation of Persons with Disabilities (Behinderungsgleichstellungsgesetz (BGG)) came into force on 1st May 2002 and was reformed in July 2016. Although the BGG was celebrated as a milestone in the German disability movement´s for equality, Degener outlines that the original document which was drafted by the Forum of Disabled Lawyers was substantially altered by the government before it came into force (Degener 2006). The BGG adopted the same definition of disability as enshrined in § 2 of the Social Code Book IX (see above). In contrast to the non-discrimination and equality definition of the CRPD[70], § 7, sentence 2 of the initial BGG defined discrimination as an unjustified unequal treatment of disabled people that leads to an unequal social participation. This initial definition neglected the fact that formal equality often leaves disabled people in a disadvantaged position (Quinn and Degener 2002b; Bundesministerium für Arbeit und Soziales 2014b). The initial BGG did not acknowledge that for disabled people to achieve *de facto* equality, different treatment and positive discrimination measures are often necessary (see Chapter 2.2.4). These issues have been addressed in the amendment of the BGG (Bundesministerium für Arbeit und Soziales 2016a). The amendment puts the main emphasis on accessibility and extended the definition of discrimination. Within the new act, the denial of necessary social provisions and accommodations is also considered discriminatory; consequently indirect discrimination is addressed. Nevertheless, the BGG only applies to the public sector. Public buildings, for example, need to be made accessible; however, the private sector and hence the majority of businesses and enterprises have no obligation under the Act. Therefore the buildings of private companies do not have to comply with accessible standards.

[70] See Article 5 CRPD, or Chapter 2.2.4 of this paper.

Discrimination in working life is not covered by the BGG. However it is addressed by the General Equality Act [Allgemeines Gleichbehandlungsgesetz, AGG] and Social Code Book IX [SGB IX]. In § 154 SGB IX, it is enshrined that employers are not allowed to discriminate against severely disabled employees on the ground of their disability[71]. Additionally § 164 requires employers to examine if a vacant position can be given to a severely disabled person. Under §164 employers are required to work close with the employment agency or the Integration Offices who are able to suggest severely disabled employees. Whenever an employer receives an application in which the applicant discloses that s/he is severely disabled, the employer has to consult the severely disabled people ombudsmen of the company (if there is any). Employers are obliged to facilitate training opportunities for their severely disabled employers and to adapt workplaces (paragraph 4). All employers who offer jobs and/or training for people with severe disabilities can receive public funding and information as well as consultation by the so called Integration Offices [Integrationsämter] or the employment agency. The Integration Offices are special advice offices that aim to support the employment of severely disabled people. The employment discrimination obligation was enacted with the intention to translate the EU equality directive 2000/78/EG of 2000 in the German system. However, § 81 does not fulfil the obligations of the EU equality directive; On the one side, it only applies to persons who have been classified as s*everely disabled*, and on the other side, most of the obligations under §81 only apply to people who are employed but not to unemployed people seeking for a job (Deinert and Neumann 2009, 57; Degener 2006; Ritz 2011, 426–27). Case law[72] shows that it is difficult to prove that a job application has been

[71] The German text reads (2) „Arbeitgeber dürfen schwerbehinderte Beschäftigte nicht wegen ihrer Behinderung benachteiligen.“ The legislation only addresses severely disabled employees.

[72] 287 judgments have been made in the case where a disabled jobseeker felt discriminated in the application process on the grounds of his/her disability (the first case dating back to 1982) [cases available at http://www.rehadat-recht.de/de/benachteiligung/benachteiligungsvorwuerfe-unterschiedliche-diskriminierungstatbestaende/benachteiligung-bei-der-arbeitsplatzsuche-im-bewerbungsverfahren/, date of last access 21/09/2018].
63 judgements have been made in the case where the disabled plaintiffs have made a case due to discrimination at the workplace on the ground of disability (§ 81, paragraph 2 SGB IX), [http://www.rehadat-recht.de/de/benachteiligung/benachteiligungsvorwuerfe-unterschiedliche-diskriminierungstatbestaende/benachteiligung-im-arbeitsverhaeltnis/?wsdb=REC&from=1&anzahl=55&artrec=urteil&themen=%22Behinderung+und+Arbeit%22+nicht+Arbeitsplatzsuche+%2F+Bewerbung*, date of access 21/09/2018]

denied due to an applicant´s disability[73]. Whereas it is against § 81 SGB IX paragraph 2 to ask if an applicant has a disability, it is lawful to ask what provisions/ accommodations are necessary to adapt the work/workplace. The employer is not obliged to disclose the reasons for a rejection. It is up to the applicant to prove that his/her disability was the ground for the rejection. If the job applicant does not mention his/her disability within the application process, he/she has no right to make a complaint under § 81 SGB IX[74]. In contrast to private enterprises, public entities have the obligation to invite the applicant to a job interview, if the applicant mentions his/her disability in the application[75] (§82 SGB IX). However, case law shows that public enterprises fail to fulfil this obligation[76]. The report on discrimination in Germany shows that between 2013 and 2016, 720 consultation requests were made to the Federal Government Commissioner for Matters relating to Disabled Persons that addressed the area of work and employment (Antidiskriminierungsstelle des Bundes 2017, 73). In particular jobseekers with disabilities felt discriminated. They experienced not being invited to job interviews despite their qualifications. The report recommends to enforce employers' obligation to disclose the reasons for the denial (Antidiskriminierungsstelle des Bundes 2017, 21). In general, scholars conclude that Germany is struggling with the implementation of equal opportunities for disabled people (Frehe 2013; Degener 2006) and that the classification into severely and not severely disabled people is insufficient and not in line with the obligations under the CRPD (Deinert and Neumann 2009; Ritz 2011, 426). Discrimination for the second group - disabled people who are not classified as severely disabled - is only covered

[73] There must be a direct link between the disability of the applicant and the refusal of the rejection by the employer. See http://www.rehadat-recht.de/de/benachteiligung/benachteiligungsvorwuerfe-unterschiedliche-diskriminierungstatbestaende/benachteiligung-bei-der-arbeitsplatzsuche-im-bewerbungsverfahren/stellenbesetzungsverfahren-privater-arbeitgeber/?wsdb=REC&from=1&anzahl=108&artrec=urteil&themen=NEUEINSTELLUNG+%2F+STELLENBESETZUNG+NICHT+PERSONALAUSWAHL+%C3%96FFENTLICHER+ARBEITGEBER [last accessed on 05/03/2017]

[74] ArbG Bielefeld Urteil vom 05.10.2011 - 6 Ca 1066/11

[75] The only exception is when the applicant does not fulfil core skills, necessary for the vacant position (§ 82 SGB IX)

[76] BAG 8. Senat - 8 AZR 375/15 - 11.08.2016.

under the General Antidiscrimination Act and therefore is unsatisfactory (Ritz 2011, 426–27).

Employment quota

Under Article 27 of the CRPD, state parties are also obliged to "ensure that persons with disabilities are employed in the public sector" (paragraph (e)) and to "promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures" (paragraph h). In contrast with many other countries (e.g. Portugal), the disability quota in Germany applies to both private and public employers. Under §§ 154 SGB IX public and private employers with 20 or more employees are obliged to employ at least 5% people with a severe disability. Special attention needs to be paid to disabled women and more severely disabled people.

The employment quota in Germany was already introduced in 1918. Back then it only aimed to support insured war veterans. The last changes to the current employment quota have been made in 2000. Before 2000 the employment quota was 6% for all employers with 16 or more employees[77]. The employment quota is mostly fulfilled by public employers. Many private employers, who offer the majority of jobs (more than 90%) do not fulfil their obligation under the employment quota (Banafsche 2012, 4; Rauch 2005, 33). In 2015, the employment quota for private enterprises was 4,1 % and for public employers it was 6,6 %. The overall employment quota was 4,7 %[78]. Employers who are addressed by the employment quota[79] are required to submit the relevant data to the Integration Offices once-a-year. The Integration Offices publishes a yearly report. The numbers are available online[80]. However, no information can be found which employers fulfil or do not fulfil their obligation under the

[77] Due to the change fewer employers were affected by the employment quota which led to a statistical increase of employers who fulfil the employment quota. Studies show, that in real life, the change had no effect on the employment of people with disabilities (Rauch 2005).

[78] 4,7% in West Germany and 4,6 % in East Germany

[79] Employers with more than 20 employees.

[80] Statistics are available online at https://statistik.arbeitsagentur.de [last accessed 08/10/2017]

employment quota. Studies indicate that companies often use the preventive measure of “occupational integration management“ (betriebliches Eingliederungsmanagement) (§ 167 SGB IX) to recruit disabled people from their own workforce (Kardorff and Ohlbrecht 2013; Niehaus 2008). The occupational integration management was introduced on 1st May 2004 to support and protect employees who are affected by health issues. § 167 SGB IX outlines that employers have to offer employees who are more than six weeks unable to work an occupational integration management. The occupational integration management consists of different stages, first the employer has to clarify if work conditions lead to the inability to work. Furthermore, the employer has to clarify if there is support available that increases the employability of the employee. In many cases the occupation integration management involves assistance in the bureaucratic procedure of having a severely disabled status assessed. While employers are obliged to offer an occupational integration management to employees, the participation of employees is voluntary. The occupational integration management is in line with the CRPD obligation to “promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities” (CRPD Article 27, paragraph 1 (k)). The occupational integration management facilitates in particular the recruitment of severely disabled people amongst the existing workforce. Whereas the process increases the company’s quota, disabled people trying to enter a company from the outside are in a disadvantaged position. As a consequence, the so called “outsiders” are less likely to benefit from the quota system (Kardorff and Ohlbrecht 2013, 17).

Employers who do not fulfil their obligation under the employment quota have to pay a compensation levy. Since 2016 the compensation levy is 125 € per month if the employment quota is between 3 and 5 %; 220 € if the employment quota is between 2 and 3%; and 320 € if the employment quota is less than 2 %. The compensation levy has to be paid for every required work place that is not filled with a disabled employer. The penalty fine has been increased in 2016, however, it has been argued that the measure is ineffective and fails to increase the employment of disabled people; in particular it has only limited effect on big companies (Kardorff and Ohlbrecht 2013; Rauch 2005; Fietz, Gebauer, and Hammer 2011). The money from the compensation

levy is used to support other measures that aim to include people in the open labour market, such as assistive devices, work assistance, and so on. This means that, if more employers fulfil their obligation under the employment quota, less means are available to support disabled people's inclusion in the open labour market (Becker 2015, 49). These circumstance leads to what Honneth and Sutterlüty called a "normative paradox" (Honneth and Sutterlüty 2010).

Ombudsman

§§177 SGB IX addresses the right to elect an ombudsman for severely disabled people and a deputy if an enterprise employs more than five severely disabled people on a permanent basis. The ombudsman for severely disabled people is elected in a confidential election. All severely disabled employees are entitled to vote. The mandate as an ombudsman is an honorary position. Although by law it is not obligatory, the ombudsman is usually disabled him/herself. In companies with more than 100 severely disabled employees, the ombudsman has the right to be exempted from his/her usual work tasks. In reality however, the ombudsmen often has to justify and fight for such exemptions from work (EU.GE.BW.A.07 2015). The task of the ombudsmen is to support and monitor the rights of disabled employees. In cases where severely disabled person mentions his/her disability in the application, the ombudsman is required to take part in the application process. The ombudsman also assists employees in the application process to obtain a severely disabled status and takes part in the process of the occupational integration management. In doing so, the ombudsman contributes to paragraph (b) of Article 27 of the CRPD, as he/she protects employed disabled people to gain just and favourable conditions of work, including protection from harassment, and the redress of grievances. Furthermore the ombudsman ensures that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others.

Dismissal protection and additional annual leave

To support safe and healthy working conditions for disabled people, the German legislation maintains a special dismissal protection for severely disabled people (§§ 85–92 SGB IX). The special dismissal protection was first implemented in 1923. The

dismissal protection means that in the cases in which a severely disabled employee is dismissed, the Integration Office has to approve the dismissal. Whereas the dismissal protection aims to protect disabled people from dismissal based on their disability, studies indicate that enterprises – in particular the ones which do not employ people with disabilities – see the special dismissal protection as a barrier to employ people with disabilities (Rauch 2005; Fietz, Gebauer, and Hammer 2011). The preconception that it is impossible to dismiss a severely disabled employee is widespread. However, the numbers show that nearly all dismissals are approved by the Integration Offices. Another measure which serves as a barrier for employers rather than an incentive are the five additional days of annual leave a severely disabled employee is entitled to under German legislation (§ 125 Abs.1 SGB IX). The legislation does not include a compensation for the company.

Financial incentives

Employers can receive subsidies for an apprentice's or the employee's pay when they employ a disabled person. The German legislation provides such benefit under § 50 SGB IX and under § 90 Social Code Book III[81]. Based on the individual and his/her limitation to participate in working life, the subsidies can cover up to 50% of the employee's pay for a time period of 12 months[82]. If necessary the amount can be increased to 70 % and the support period can be extended to 24 months (after 12 months the wage subsidies is reduced by at least 10 %)[83]. The legislation entails the possibility that an employer is asked to reimburse part of the subsidy if a subsidised worker is dismissed during a "protection period" which encompasses the subsidisation period and an obligatory follow-up period of the same length. Between 2007 and 2010, annually there were more than 250.000 jobs subsidised[84] (Brussig, Schwarzkopf,

[81] SGB III "Employment Promotion", entails different measures to support the employment, not only for disabled people but for different groups, e.g. women (§ 8 SGB III)

[82] In case of an apprenticeship the subsidies can cover up to 60% of the monthly wage of an apprentice's pay for the time of the apprenticeship, which is in general 3 years.

[83] In cases, where the disabled employee is older than 50 years, the support period can be extended to 36 months and in severe cases the support period can be extended to 60 months or 96 months (if the employee is older than 55).

[84] This study covers all subsided jobs, not only the ones for persons with disabilities. In Germany,

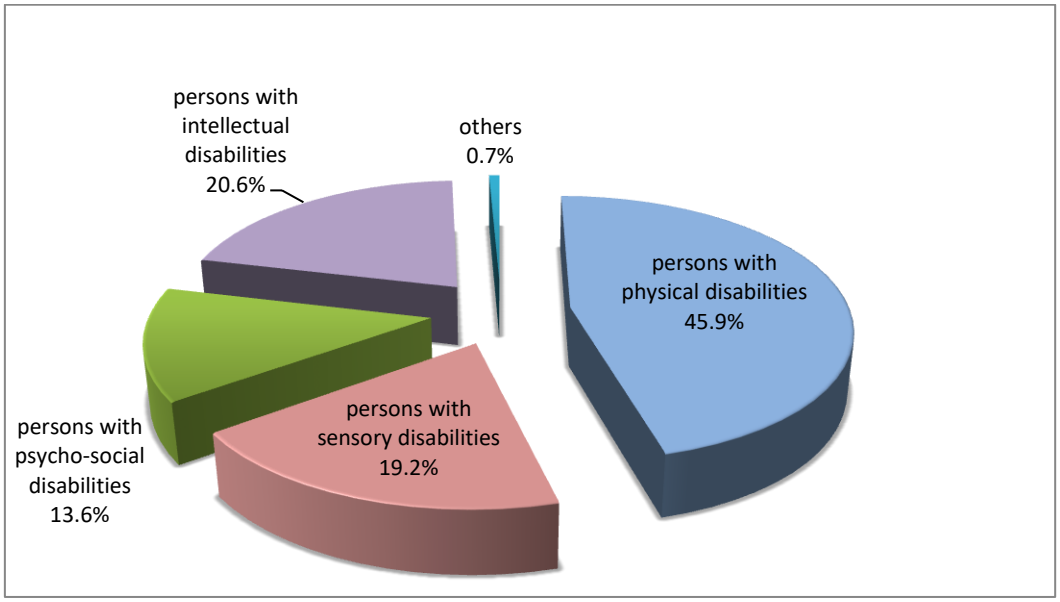
and Stephan 2011). Studies indicate that the integration incentives are an important measure which influences the hiring decisions of employers (Brussig, Schwarzkopf, and Stephan 2011; Fietz, Gebauer, and Hammer 2011; ZEW, IAB, and IAT 2006). Scholars found that, in particular the protection period, has a positive impact on the ongoing employment of subsidised disabled employees (Brussig, Schwarzkopf, and Stephan 2011). However, the formal application and bureaucratic procedures are very complex. Especially smaller companies have limited knowledge about the subsidies and fear the bureaucratic barriers (ZEW, IAB, and IAT 2006, 89; Brussig, Schwarzkopf, and Stephan 2011)[85].

The evaluation study of the Federal Programme Job 4000 offers interesting insights on how people with different types of disabilities benefit from employment subsidies. The Programme Job 4000 took place during 2007-2012 and was funded with 31.25 Million by the Federal Ministry of Labour and Social Affairs. The main objective was to support the integration of severely disabled people in the open labour market. The programme was divided in three areas; (1) employment, (2) vocational training, (3) support through the Integration Office. The evaluation, which was conducted in 2014, shows that in the area (1) "employment" 1000 new jobs for people with disabilities were created through the provision of comprehensive subsidies to employers. The statistics (figure 5) show that the majority of people supported in area 1 of the programme were people with a physical disability. This group made up 45,9% of the total number of beneficiaries.

subsidies are also provided to employers who employ other disadvantaged groups, such as long-term unemployed.

[85] On 4th April 2014, the CRPD Committee decided in the Case of Gröninger vs Germany. Communication No. 2/2010: "In the instant case, the Committee is of the view that the existing model for the provision of integration subsidies does not effectively promote the employment of persons with disabilities. The Committee finds in particular that the apparent difficulties faced by potential employers when trying to access the integration subsidy that they are entitled to for the employment of a person with disabilities affect the effectiveness of the integration subsidies scheme. The already mentioned administrative complexities put applicants in disadvantageous position and may in turn result in indirect discrimination. The Committee therefore considers that the integration subsidies scheme, as applied in the author's son's case, is not in accordance with the State party's obligations under article 27, paragraph 1(h), read together with article 3, paragraphs a, b, c and e, article 4, paragraph 1(a) and article 5, paragraph 1 of the Convention."

Figure 5: Programme Job 4000, Participants by type of disability



Source: BMAS 2014

Furthermore, the study results indicate that in particular people with intellectual and psycho-social disabilities need time and cost intensive support and, despite all efforts and support people with these types of disabilities in particular were more likely to return to sheltered employment after the subsidised period (Bundesministerium für Arbeit und Soziales 2014a). For people with complex support needs that require ongoing support, such as people with severe and psycho-social disabilities, the subsidies are not sufficient as they have a time limitation (Fietz, Gebauer, and Hammer 2011; Bundesministerium für Arbeit und Soziales 2014a; Fuchs 2013). The same applies to the trial period measure under § 46 SGB III. § 46 SGB III offers a reimbursement for a period of up to three months, if an employer is unsure about the employment of a disabled person. All these measures aim to "promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment" (CRPD, Article 27, (h). In 2014, the Committee on the Rights of Persons with disabilities observed, at its 11th session (31 March- 11 April 2014), that the said scheme in practice requires employers to go through a complex additional application process, the duration and the outcome of which are not certain and that the disabled person has no possibility to take part in the process. Furthermore, the Committee concluded that the policy seems to respond to the medical model of disability, because

it tends to consider disability as something that is transitional and that, in consequence, can be “surpassed or cured” with time. The Committee is of the view that the existing model for the provision of integration subsidies does not effectively promote the employment of persons with disabilities. The Committee therefore considered that the integration subsidies scheme is not in accordance with the State Party’s obligations under article 27 of the Convention on the Rights of Persons with Disabilities. A further study conducted in 2011 strengthens the critics made by the Committee. The study concluded that integration subsidies are an important measure to promote the employment of disabled people, however, the complex administration procedure and the different varieties affect the effectiveness of the integration subsidies scheme (Brussig, Schwarzkopf, and Stephan 2011). Another study (Fuchs 2013) found that for one part of the subsidised workers, the ones with the highest level of employability, the incentives worked as a door-opener to the first labour market. They could sustain their employment after the subsidised period. However, for people who are considered unable to participate in work processes such as people with very severe, high and complex support needs, there was no realistic chance to continue without support. Their employment was often terminated after the subsidised period. Fuchs is calling the second group the “losers of modernisation“ (Fuchs 2013, 306). Despite the obvious need for a long-term support, the German government abolished a subsidy without time limitation, which was provided under § 16e SGB II in 2012 and reduced the support time to a maximum time period of 24 months (Fuchs 2013). As a consequence, people with severe, complex and high needs are less likely to benefit from the programme, whereas in particular people with physical and sensory disabilities benefit from the subsidies.

Workplace adaptations

Article 27 “further requires that states parties ensure that reasonable accommodation is provided to persons with disabilities in the workplace and work” (Article 27, 1 (i). In Germany adaptations of the workplaces, adaptive technologies and special equipment at work are funded under SGB IX. As outlined above, in contrast to public enterprises private entities are not covered under the Act of Equalisation of Persons with Disabilities (BGG). Therefore private enterprises are often not accessible

and workplace adaptations are required if a disabled person works in the company. To obtain the benefits a formal application needs to be logged to the Integration Offices. Once more the benefits are highly individualised and require complex bureaucratic procedures as the funding varies according to the origin of the disability and the employment status of the disabled person. The decree on Workplaces [*Arbeitsstättenverordnung/AstV*][86] includes regulations on accessibility, such as the accessible design of workplaces, doors, escape routes, stairs, toilets, and so on. However, the degree is only applicable in companies that already employ persons with disabilities. Consequently, companies are afraid to hire persons with disabilities, because they fear the costs arising from retrofitting (BRK-Allianz 2013, 17).

Work assistance

Work assistance can be obtained if a disabled employee needs ongoing support at the workplace and workplace adaptations or the provision of technical devices are not sufficient (SGB IX, § 185, paragraph 6). To be eligible for work assistance, disabled people need to be fully qualified for the job. Furthermore, some form of ongoing assistance to fulfil job tasks is required. For example, a hard of hearing person who is fully qualified to do the main job tasks might need someone answering the phone a couple of hours per week. The measure was introduced in 2002 and is mainly used by people with physical or visual disabilities (Blesinger 2005; Landschaftsverband Rheinland Integrationsamt 2007, 103). Studies indicate that there is also gender bias; disabled men are more likely to use the measure than disabled women (Landschaftsverband Rheinland Integrationsamt 2007, 103). Work assistance is funded through the compensation levy and therefore only applies to severely disabled people. Furthermore, the assistance depends on the availability of means. The costs for work assistance are to be seen in relation to the employer's income, and they should be less than 50 % of the disabled employer's gross income. Work assistance can be organised in two different ways - through the employer model or through the provision of services. In the first model, the employer model, the disabled person is responsible for the organisation and the employment of the assistance. The formal procedures to

[86] § 15, AstV, version from April 29, 2012.

obtain work assistance include administrative complexities (Blesinger 2005, 291; Landschaftsverband Rheinland Integrationsamt 2007).

Supported employment

Despite the variety of measures available, there are still ongoing debates about the inclusion of people with intellectual disabilities. Many of the measures outlined above are insufficient, as they either offer support only for a specific time period (financial subsidies, trial period) or require a high level of education and self-organisation (work assistance). The measure of supported employment was introduced on 1st January 2009 to close this gap. Supported employment § 55 SGB IX aims to offer in particular persons with intellectual disabilities an appropriate and adequate support to secure and maintain paid employment in the open labour market because for many people with an intellectual disability, participation in the world of work is still restricted to sheltered employment (Kainz 2012; Schulz and Bungart 2014, 4). Supported employment is divided in two different stages. In the first stage the disabled person is profiled and then placed and trained by a job coach in a particular workplace that fits the qualifications of the disabled person. This stage may take up to two years. During this time, the disabled person is not employed by the employer. After the workplace training, the second phase starts: If the disabled person obtains a working contract of at least 15 hours a week, ongoing support is provided. Supported employment is funded by the Employment agency (first stage) and the Integration Offices (second stage). Whereas the funding in the first stage does not depend on the degree of disability, the funding in the second stage depends on the degree of disability, as the Integration Offices only support people who are officially classified as severely disabled. The numbers from 2015 indicate that 79 % of the people who entered stage 2 of supported employment relied on financial incentives to employers, and only 16,5% entered the second stage without an incentive paid to the employer (Schulz and Bungart 2016, 10). The majority of people supported through the measure are people with intellectual disabilities (see table below) (Schulz and Bungart 2016, 4).

Table 5: Supported Employment in Germany, participants by type of disability in 2015, 2009-2014

Supported Employment, Participants by type of disability

	2015	2009-2014
Learning and intellectual disability	**59,6%**	**67,5%**
Psycho-social disability	**25,0%**	**17,2%**
Physical or sensory disability	**10,3%**	**10,2%**
Other disabilities	**2,5%**	**3,2%**
Not specified	**2,6%**	**1,9%**

Source: Schulz and Bungart 2016.

The numbers of 2015 further indicate that more men (68,3%) are supported by the measure than women (31,7%). The participants cover all ages, however young people, aged between 18-24, make up more than half of the participants in 2015 (see table below) (Schulz and Bungart 2016, 4–5).The numbers indicate that the measure addressed in particular school leavers. In doing so, supported employment provides an alternative to the vocational training in sheltered employment.

Table 6: Supported Employment in Germany, participants by age

Supported Employment, participants by age		
	2015	**2009- 2014**
Younger than 18	4,6%	4,3%
18 – 24 years	57,1%	61,9%
25 – 40 years	32,4%	29,6%
Older than 40	5,9%	4,1%
No reference	0,0%	0,1%

Source: Schulz and Bungart 2016.

In regards to their education, 59,2 % of the participants had attended a special school, 20,1 % have completed nine years of school , 7,9% 10 years of school, and 3,6 % have completed high school and 7,5% other schools (Schulz and Bungart 2016, 5). These numbers indicate that the measure has been successful in reaching its target

group, school leavers from special schools who might have been in the past admitted to sheltered workshops.

Inclusion companies (former integration projects)

For severely disabled people, Inclusion Companies offer another possibility to participate in work. Inclusion companies (prior to the BTHG, "Integration Projects") are subsidised companies or departments of a company that employ at least 30 % of severely disabled people (until 2017 at least 25 %). The first integration companies emerged in the 1970s as self-help projects of people with psychosocial disabilities and their supporters (Schwendy and Senner 2005). Integration projects have been introduced in 2001. The aim is to offer an employment opportunity for people with psychosocial and mental disabilities. However, the majority of people working in integration projects are people with physical disabilities (Detmar et al. 2008, 9). In 2015 there were 847 Integration projects employing in total 25.937 people. 11.443 severely disabled people were among the employees making up 44 % of the total workforce in inclusion companies[87].

Sheltered employment

Whereas most of the measures in place are offering time limited support or only support to severely disabled people, the system of sheltered employment (WfbM) in Germany provides unconditional support to people with disabilities. Although at the beginning designed for people with intellectual disabilities[88], workshops are nowadays open to all disabled people who, on account of the nature or severity of their disability, cannot (yet) enter or re-enter the open labour market. There is no obligation to be classified as severely disabled. Disabled people have the right to work in a sheltered employment as long as they are able to produce 'a minimum amount of economically useful work' (§ 56, § 219 SGB IX). By legislation, disabled people working in sheltered

[87] Numbers retrieved online from http://www.bag-if.de/integrationsunternehmen-in-zahlen/ [access date: 26/03/2017].

[88] In Germany, sheltered employment was introduced in 1974. The severely disabled act of 1974 mentioned sheltered employment in § 52. The main goal of sheltered workshops was to offer mentally disabled people, who could not be included in the open labour market, a place to work and to develop and sustain their skills.

workshops are not considered as workers (§ 221 SGB IX). Therefore they are not covered by national or EU labour law[89]. To be admitted to a sheltered workshop it must be assured that no extraordinary care needs exist and that no endangerment is given to others or the person herself. There is a very specific structure in sheltered employment consisting of three stages, namely the admission procedure, the vocational training stage and the working stage. The admission procedure for employment in a sheltered workshop takes up to three months. Based on the place of residence and the prerequisites under §§ 56 and 219 SGB IX, it is decided if the sheltered workshop is suitable for the disabled person. In Germany there are many disability-specific sheltered workshops. The decision about which workshop is most suitable is made by an expert committee. The results of a comprehensive study indicate that two thirds of the sheltered workshops did not include the voices of the disabled person nor that of his/her legal representative in decision making processes (Detmar et al. 2008, 152). In Germany the system of sheltered employment is widespread and diverse: in 2016 there were approximately 300.000 people with disability employed in more than 700 sheltered workshops[90]. Although they are not employed in the open labour market, people with disabilities who work in sheltered workshops are not counted as 'unemployed' in official labour data statistics. By law, people with disabilities who are employed in sheltered workshops are officially receiving employment participation benefits

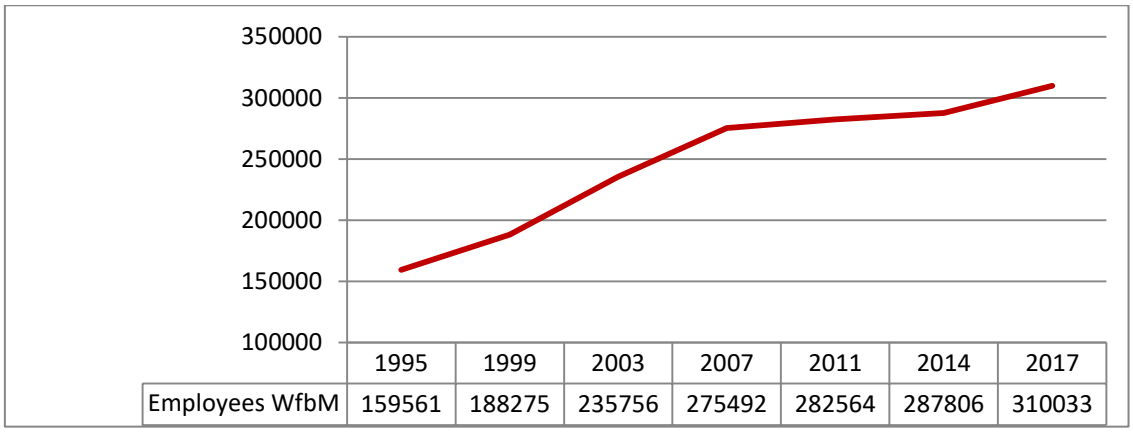
A comparative study conducted in 1998 (Visier 1998) reveals that Germany has one of the highest number of people employed in sheltered workshops within the Council of Europe. Considering recent numbers, not much has changed since. A comprehensive study about the 'development of the admission numbers of sheltered workshops' (Detmar et al. 2008) revealed that between 2001 and 2006 the number of persons

[89] In the case of Fenoll (France), the European Court (First chamber) has ruled that "the term 'worker' within the meaning of Article 7 of Directive 2003/88/EC of the European Parliament and of the Council of 4 November 2003 concerning certain aspects of the organisation of working time, and of Article 31(2) of the Charter of Fundamental Rights of the European Union, must be interpreted as meaning that it may include a person admitted to a work rehabilitation centre, such as that in the main proceedings" (Judgment of the Court, C-316/13, 6/03/ 2015)

[90] After a high rise between 1994 and 2007, in which the numbers of people working in sheltered employment rose from 152.501 to 275.492 numbers stagnate around 300.000 during the last view years. Figures are available online at http://www.bagwfbm.de/page/25 [date of access 04/05/2017]

working in sheltered workshops has constantly increased. Furthermore a survey on the current situation and the future need of sheltered workshops predicted that until the end of 2010 there will be an increase to approximately 254.000 disabled people working in sheltered employment. However, it was forecasted that after 2011 the numbers of people being employed in sheltered employment would decrease (Hartmann and Hammerschick 2003). Nevertheless, in 2005, there were already 268.000 people employed in sheltered employment and the numbers have since continued to increase to a total of 310.033 in 2017 (BAG WfbM 2017). An annual increase of 3% is ongoing (see chart below).

Graph 15: Numbers of people working in sheltered workshops, 1995-2017



	1995	1999	2003	2007	2011	2014	2017
Employees WfbM	159561	188275	235756	275492	282564	287806	310033

Source: BAG WfbM 2017

The ongoing increase of admission numbers occurred despite decreasing overall unemployment rates in Germany (Detmar et al. 2008, 111). In regard to the legal obligations under the Social Code Book IX, sheltered workshops must enable a disabled person to 'maintain, develop, improve or recover his/her ability to work and his/her work performance to further develop his/her personal identity (§ 58 SGB IX). Sheltered workshops aim to support the transition into the open labour market (§ 58 SGB IX, para. 2, sentence 3). The low transitions rates from sheltered employment to the open labour market (only 0,16% between 2002 and 2006 according to Detmar et al. (2008, 111) has been widely condemned. Scholars (Welti 2017) and disability activists (Bentele 2017) argue that the dual role of sheltered workshops in Germany serves as an obstacle: On the one side, sheltered workshops and the (non-disabled) people being employed in sheltered workshops (supervisors, social workers and others) depend on the numbers of disabled people being admitted to sheltered

workshops[91]; on the other side, the same people are responsible for the transition into the open labour market. If too many disabled employees are transferred to the labour market the non-disabled people working in sheltered workers, such as supervisors, social workers and others fear to lose their jobs.

People with disabilities who are admitted to sheltered workshops are classified as *permanently unable to work*, which requires an inability to work of at least three hours per day under normal working conditions (§43 SGB VI). This prerequisite becomes a further obstacle in the transition process. Workers in sheltered workshops fear that they lose their entitlement to obtain a reduced-earning-capacity pension[92] if they attempt to make the transition into the open labour market (Ritz 2009). This obstacle has been addressed in the BTHG. From 2018 onwards, people with disabilities have a right to return to sheltered workshops if their transition to the open labour market has been unsuccessful. On paper, the newly introduced BTHG addresses many of the issues previously outlined. Since 1st January 2018, the rights of people with disabilities working in sheltered workshops (WfbM) have been strengthened. Under the amended SGB IX, the WfbM committees [Werkstatträte] that represent the interests of WfbM employees have more saying in regard to working conditions, such as working hours, reimbursement and technical equipment, as well as further training and social activities. Furthermore a women representative is obligatory, being responsible for the disabled women working in sheltered workshops. Further changes that came into force on 1st January 2018, aim to alter the present system: New providers are able to offer sheltered employment and the Job Budget ("Budget für Arbeit") is introduced - people who are entitled to work in a sheltered employment have the opportunity to receive a cash benefit that enables them to pay up to 75% of the gross income to an employer if the employer provides them with an employment in the open labour market. Nevertheless, the new legislation makes no changes to the entry prerequisite to

[91] People with disabilities who work within sheltered workshops as "Beschäftigte/clients" have a different labour status than people who work within sheltered workshops as supervisors, social workers, and so on. Disabled people who are admitted to sheltered workshops under § 56 SGB IX have a quasi-employee status (Visier 1998, 358) which means that they are not covered under the labour act.

[92] After 20 years in a sheltered employment, disabled people are entitled to receive a full reduced-earning-capacity pension.

achieve a 'minimum amount of economically useful work' and to the very low reimbursement in sheltered workshops, although this has been a major subject of criticism (Ritz 2009, 698). In Germany, the minimum wage[93] does not apply to people working in sheltered workshops. In 2010, the average salary of disabled people working in a sheltered workshop was 180 Euro/month[94]. People working in sheltered employment are entitled to social security and to an incapacity pension. As the numbers below show people with intellectual disabilities dominate as a group in sheltered employment (see graph 16). The second strongest group are people with a psychosocial disability.[95] Recent figures indicate that the admission numbers of people with psychosocial disabilities is further increasing.[96] Today, people with psycho-social disabilities already make up 37 % of all applicants in the admission procedures (BAG WfbM 2014).

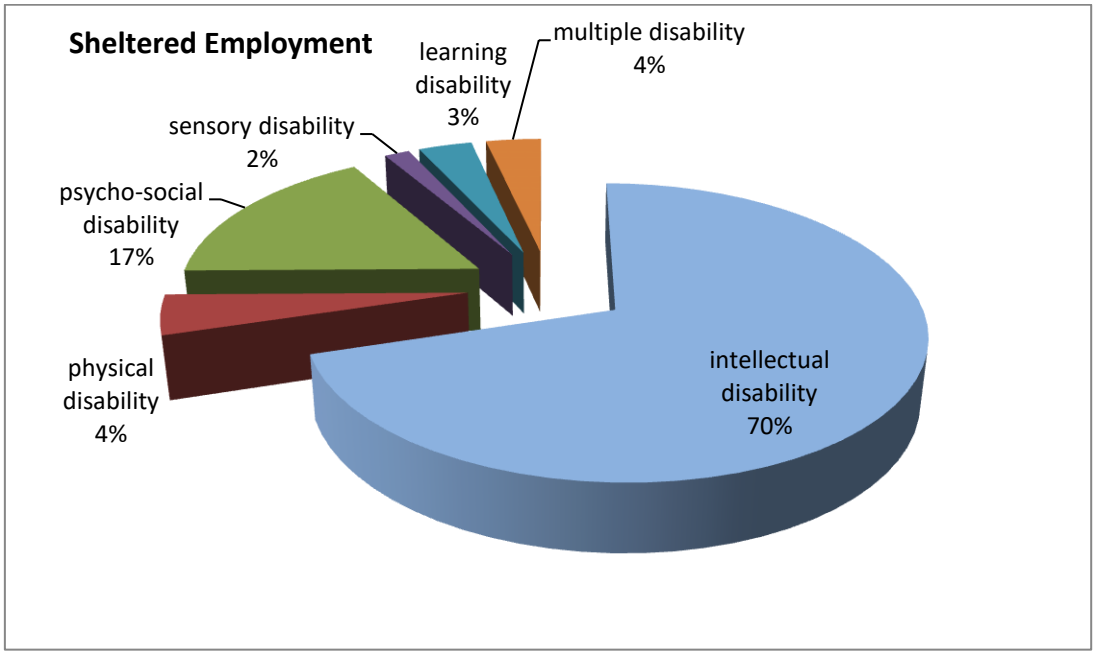
[93] In Germany the minimum wage was only introduced in June 2016. On 1st July 2017, it was 8,84 €/hour.

[94] Quoted in: Bundesarbeitsgemeinschaft Werkstätten für behinderte Menschen e.V.: http://www.bagwfbm.de/page/101 [access date: 25/03/ 2017)

[95] Considering the type of disability, the figures from 2006 are: intellectual disability: 70,3%, physical disability: 4,5%, psychosocial disability: 16,7%, sensory disability 1,6%, learning disability: 3,4%, multiple disabilities 3,5% (ISB 2008).

[96] BAG WfbM, 2012: Intellectual disability: 77,49 %, psycho-social disability: 19,18 %, physical disability: 3,33 %.

Graph 16: Percentage of people working in sheltered workshops by type of disability



Source: ISB 2008

In regard to Visier's classification of types of sheltered employment situations, Germany is grouped within the 'intermediate model', in which the disabled worker is perceived as 'quasi-employee' (Visier 1998, 358)[97]. Considering in particular the low transition rate, the assessment procedure and the work conditions the German system of sheltered workshops is not in line with Article 27 of the CRPD. In particular the right to just and favourable conditions of work , including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances are violated (Palleit 2016). As outlined in Chapter 3.3, the CRPD demands the abolition of segregated sheltered employment. However, scholars argue against this radical view and advocate instead for the strengthening of the individual choice: Disabled people should have real choices in regard to employment. For the ones who choose sheltered employment the special settings should exist (Trenk-Hinterberger 2016, 110; BAG WfbM 2014, 7).

Concluding remarks

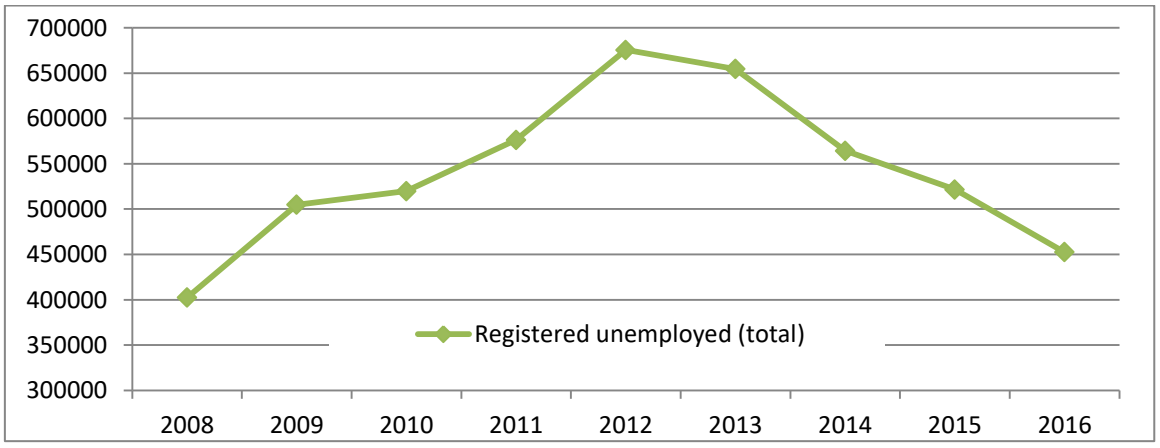
[97] Visier distinguishes between fours models: the therapeutic *model*, the intermediate model, the mixed (dual) model, and the wage employment model (Visier 1998).

The monitoring of the German employment policies and legal framework has shown that the present system has emerged over the last century, first measures, such as the dismissal protection or the employment quota has been implemented at the beginning of the 20th century as a response to the increasing numbers of injured war veterans. Overall the German employment support system is complex and bureaucratic on the one hand and segregative on the other hand. In particular the division between severely disabled and disabled people contributes to its complexity. While some measures, such as employment incentives, work assistance, second stage of supported employment and many more are only available to people who are classified as severely disabled, other measures and programmes such as sheltered employment, the first stage of supported employment are available to all disabled people. The bureaucratic procedures and the existence of a comprehensive and widespread sheltered employment system leads to the outcome that many disabled people with high and complex needs end up in sheltered workshops. Although recent measures, such as the Job Budget aim to address the segregation in the labour market, outcomes of the success of such measures are outstanding. The following analysis of the Portuguese employment system will show how the situation differs in a country in which less segregated employment opportunities exist.

6 Disability employment policies in Portugal in light of the Convention on the Rights of Persons with Disabilities[98]

While in Germany questions on disability are included in the Mikrozensus survey every four years and data on severely disabled people is collected on an annual basis, national publicly available data about disabled people and their participation in the labour market is scarce in Portugal. Although the Portuguese Employment and Vocational Training Institute (hereafter *IEFP*) provides data on the employment situation of disabled people, the figures only cover people who are registered at the employment agencies. The data thus exclude disabled (as well as non-disabled) people who might seek for work but who are not registered. The annual statistics of the IEFP reveal that, in the aftermath of the financial crisis, the number of all people registered as unemployed has risen from 402.545 to 675.466 in 2012. Since 2012, the numbers have been declining: between 2012 and 2016 a decrease of 33 % has occurred (see graph 17).

Graph 17: Numbers of all people registered as unemployed at the IEFP, 2008-2016 (Portugal continental)



Source: IEFP. Situação do Mercado de Emprego – Relatório Anual 2008-2016[99]

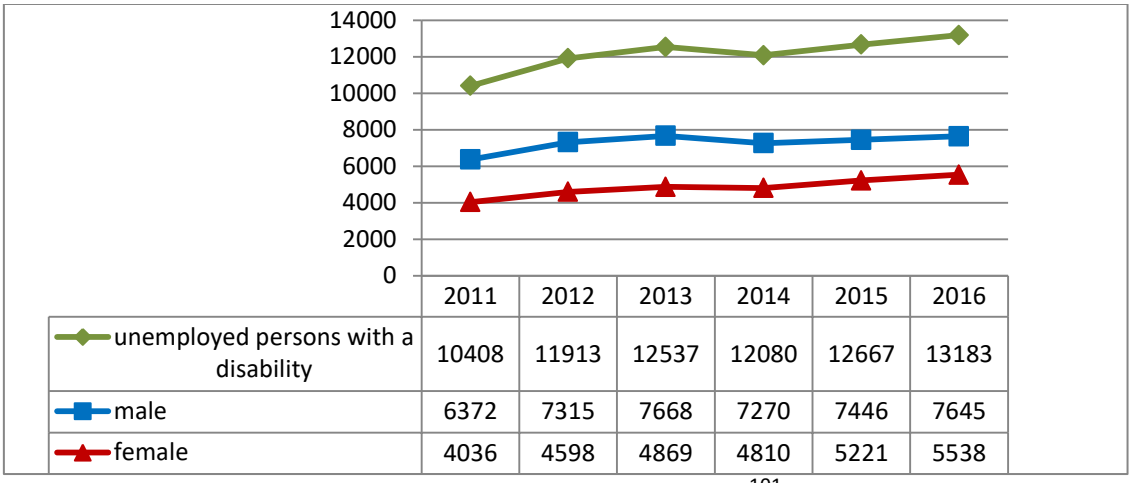
Similar to Germany, the figures of people with disabilities registered as unemployed at the Portuguese Employment and Vocational Training Institute have not

[98] The present analysis was completed in 2018 and does not include any updates or amendments made in Portuguese laws or policies after that.

[99] Data available online https://www.iefp.pt/estatisticas [date of access 10/02/ 2018]

developed in the same positive direction than the overall unemployment numbers. The numbers have instead continued to rise after 2012 (see graph 18). Although a minor drop occurred between 2013 and 2014, the overall numbers increased between 2011 and 2016 by 26 %. The increase was higher among women with disabilities – unemployment for them rose by 37 %, whereas the number of registered unemployed men increased by 20 %[100].

Graph 18: Numbers of people with disabilities registered as unemployed at the IEFP, 2011-2016 (Portugal continental)



	2011	2012	2013	2014	2015	2016
unemployed persons with a disability	10408	11913	12537	12080	12667	13183
male	6372	7315	7668	7270	7446	7645
female	4036	4598	4869	4810	5221	5538

Source: IEFP. Situação do Mercado de Emprego – Relatório Anual 2008-2016[101]

The following critical analysis of the Portuguese employment policies outlines which measures are in place - at least on the law books. Through the examination of secondary and labour statistic data, it is further shown how the measures fail to support the inclusion of disabled people in the labour market on a large scale. In contrast to the German analysis, the availability of existing studies is limited. As a critical understanding requires some knowledge of the historical roots of present policies, a brief overview of the historical development of disability policy in Portugal is provided at the beginning of the chapter. At the end it will be shown how the adoption and ratification of the international human rights framework is influencing recent and present policy directions.

[100] The rising numbers of people registered at employment centres also reflects the fact that more and more people every year are knowledgeable about the IEFP. The increase is an indication that people register to access all sorts of benefits and support programmes (including vocational training).

[101] Data available online https://www.iefp.pt/estatisticas [date of access 10/02/ 2018]

6.1 Disability policy in Portugal – the late development of the Portuguese welfare state and a prevailing strong welfare society

In the following paragraphs it is shown that in Portugal, in particular, three major events have marked the current social security system; namely (1) the Revolution of October 5th, 1910, that brought an end to the monarchy and paved the way for the first Republican regime, (2), the coup d'état of May 28th, 1926 that established a military dictatorship which was replaced by Salazar's 'Estado Novo' in 1930[102] and (3) the Revolution of April 25th, 1974, that set the ground for the current political system (Guibentif 1997).

6.1.1 The first Portuguese Republic (1910-1926)

As Guibentif outlines, when the Republic was proclaimed in 1910, the role of the Portuguese State in social affairs was a modest one (Guibentif 1997, 220). The new Constitution that came into force in 1911, introduced the "right to public assistance" (*assistência pública*) (Article 3, Section 29). Public assistance replaced the former "public charity' (*beneficiência pública*). However, charitable organisations, often run by the Catholic Church (mainly *Misericórdias*), remained the main providers of social assistance and charity after 1911. The role of the State was to supervise these organisations (Guibentif 1997, 220). In 1919, the decrees No. 5.636-5.640 of May 10th, introduced a system of compulsory social insurance which covered sickness, workplace accidents, invalidity, old age and survivors' pensions. It is argued that the new system was mainly an element of electioneering and an attempt of the Portuguese government to compete with popular international (British and German) legislations. Furthermore, social actors, such as workers' and employers' organisations and mutual insurance companies played no significant role in the drafting process of the law (Guibentif 1997, 221). Overall the new system had mainly symbolic political character, was poorly enforced and thus had only a limited effect in practice.

[102] The transition from the dictatorship to the Estado Novo was fluent; therefore discussions exist about the initial moment of Estado Novo. On May 28th 1930 António de Oliveira Salazar talked in a keynote speech about *Estado Novo* for the first time.

6.1.2 Military dictatorship and Estado Novo (1926-1974)

The military dictatorship that was installed in 1926 marked the end of the first Portuguese Republic. Political and social instability preceded the event of 1926. Gradually, the so called *Estado Novo* emerged and the new Constitution of 1933 abolished "the right to public assistance". The former right was replaced by two provisions; (1) under article 15 of the new Constitution, the State regulated the activity of associations, corporations and [workers] organisations, in particular those with objectives concerned with assistance and charity and (2) under article 41, the State promoted and supported institutions of solidarity, welfare, cooperation and mutuality. Any kind of autonomous organisation of action or discussion in civil society was diminished under *Estado Novo*. The only way a disability organisation could survive was by identifying as sport organisations and/or peer meeting groups. Under the fascist regime these organisations did not develop any political understanding of disability but rather reinforced the charitable perspective on disability (Fontes 2014, 3). The dictatorial State played only a supplementary role in the social welfare sector. Most disabled people who were unable to access the labour market relied on the support of family and kinship networks and on the few remaining charities (Fontes 2014). The Law on *Previdência Social* (Social Welfare) was passed in 1935 (law No. 1884 of 16 March 1935). Law No. 1884 encompassed a typology of four categories of social welfare institutions: (1) the *caixas sindicais de previdência social*, for specific groups of workers e.g. fishermen, (2) the so-called 'pension and welfare funds' (or company funds), (3) the mutual societies, and (4) the servants' protection institutions. In 1936, the government established a series of family benefit funds that were incorporated in the existing heterogeneous system (Guibentif 1997, 226–27).

In 1944, the Statute of Social Assistance (law No. 1998 of 15/5/1944) created the 'Institute for the Assistance of the Invalid' in order to coordinate and supervise private local initiatives. Due to the charitable framework and the constraints imposed on disabled people's organisations, disabled people were almost invisible in Portuguese society before 1974 (Fontes 2014, 3). Thus the more than 25.000 impaired Portuguese soldiers who returned from the colonial wars faced a disabling society and persisting social barriers which served as a catalyst for social change and a sense of solidarity and

collective identity (Fontes 2014). As a consequence, in the final years of the dictatorship the first organisation of disabled people emerged[103] and law 6/71 of 8 November provided a general framework for the rehabilitation of disabled people. Nevertheless, the new legislation was clearly entrenched in the medical, individual approach to disability and defined disabled people as those "who in result of an injury, deformity or disease, congenital or acquired, are permanently diminished to undertake a professional activity or to carry out daily life activities" (law 6/71, base I, no.3).

6.1.3 Second Portuguese Republic (since1974)

Authors agree that a distinctive feature of the Portuguese welfare state is its late emergence, which took place only after the fall of the fascist regime (Fontes 2009; Ferrera 1996; Adão e Silva 2002). During the dictatorship, the authoritarian regime suppressed secularisation tendencies, as well as economic modernisation and the development of liberal democratic structures (Adão e Silva 2002, 35). Only after the Carnation Revolution on April 25th 1974, there was hope for the democratisation and social and material improvement within the Portuguese society. Nevertheless, as Santos argues due to the late development of the Portuguese welfare state and the lack of institutionalisation of a fordist regulation of the wage relation, it has been impossible to develop a true welfare state in Portugal. The Portuguese State represents instead a 'quasi-welfare state' (Santos 1991, 5; 33).

Although a slow change of civil organisations for and of disabled people took place, the legacy of the dictatorship persisted in the authoritarian way in which the State related to organisations of disabled people (Pinto 2012, 178–84). In 1976, a new Constitution was introduced. The new Constitution implemented an assistance scheme for the unemployed, and a means-tested social pension, as well as a clause on the rights and duties of people with disabilities. Article 71 of the Portuguese Constitution read at the time of its introduction:

[103] In 1972 the Associação Portuguesa de Deficientes (Portuguese Association of the Disabled) was created and the Associação dos Deficientes das Forças Armadas (Association of the Disabled of the Armed Forces) was established in 1974.

1. Physically or mentally disabled citizens fully enjoy the rights and are subject to the duties enshrined in the Constitution, save for the exercise or fulfilment of those for which their condition renders them incapable.

2. The State is obliged to implement a national policy for the prevention and treatment, for the rehabilitation and integration of the disabled[104] and to educate society in such a way as to make society aware of the duties of respect and solidarity towards them, and to undertake the charge of ensuring that their rights are effectively fulfilled, without prejudice to the rights and duties of their parents or guardians[105].

Despite the creation of a universal system of social protection (Decree-law 513-L/79 of 26th of December) in 1979, the Portuguese welfare state soon turned into a selective system. Decree-law 160/80 of 27th of May introduced a non-contributory and a contributory regime that provided different levels of provision. Consequently, access to State social protection resumed the logic of social assistance for the poor, and was once again perceived as 'state benevolence' (Fontes 2009, 5; Santos 1991, 34). Fontes and others outline:

"[for disabled people and their families, the] suppression of the idea of the welfare state – with the state assuming a secondary role in providing social protection – and the affirmation of a benefits mentality in which disability mainly emerges as a charity issue has established a paternalistic logic that even today takes precedence over recognition of political and economic autonomy as a right that enriches the democratic arena" (Fontes, Martins, and Hespanha 2014, 855).

The lack of income security, the pervasiveness of traditional visions of disability, the shortage of medical and vocational rehabilitation, and the tendency of the State to make itself invisible in social areas by delegating responsibility to civil society continues to weaken the current situation of disabled people (Fontes 2014). Additionally, the

[104] Citizens with disabilities replaced the former term the disabled ('deficientes') in 1997.

[105] In 1982, a third sentence was added which reads "The State shall support disabled citizens' organisations".

existence of a strong 'welfare society'[106] (Santos 1991, 33–40) that compensates the shortages of public social provision reduces the pressure on the government to introduce a more comprehensive social security system. The so-called "Southern family" has been identified as a distinctive feature not only in Portugal but also in other Southern European welfare states (Ferrera 1996, 21; Karamessini 2007). Rather than introducing a comprehensive social protection, the Portuguese state has been promoting and financing non-profit private institutions. The role of these institutions is to provide social services under the supervision of the State. In doing so, a 'secondary civil society' which is marked by its dependence on the State has been established (Santos 1991, 36). Due to their economic vulnerability and the inadequate democratisation of relations between the State and their organisations, disabled people have scarcely been included in decision-making processes that affect their lives (Fontes, Martins, and Hespanha 2014, 855; Pinto 2012, 178–81).

Since the re-establishment of democracy, various public institutions have been founded such as the National Secretariat for Rehabilitation[107] (SNR) and the National Council for Rehabilitation[108] in 1977 (Decree-law 436/77 of 20 August). These institutions marked the beginning of the institutionalisation of disability issues (Fontes 2014). Between 1977 and 1980, the social security system was expanded and a range of disability benefits were introduced that addressed families that have members with disabilities. Additionally, measures were introduced in the tax system to specifically benefit people with disabilities, such as tax exemptions for the purchase of mobility devices or an adapted vehicle[109] (Pinto 2011a, 120). However, the entitlements were usually low and family and relatives often had and still have to compensate for the lack of sufficient social assistance. In 1989 the 'Prevention, Rehabilitation and Integration

[106] Santos defines the 'welfare society' as followed: "networks of relationships of inter-knowledge, mutual recognition, and mutual help based on kinship and community ties, through which small social groups exchange goods and services on an nonmarket basis and with the logic of reciprocity" (Santos 1991, 37).

[107] Instituto Nacional para a Reabilitação

[108] Conselho Nacional para a Reabilitação e Integração das Pessoas com Deficiência

[109] Decree-law 269/75 of 30 May

of People with Disabilities Act'[110] was introduced. As Pinto outlines the bill advanced a new definition of disability, based on the International Classification of Impairments, Disabilities and Handicaps, which had been adopted by the World Health Organisation in 1980:

> "A person is considered disabled when by lack or anomaly, congenital or acquired, of a psychological, intellectual, physiological or anatomic structure or function likely to produce restrictions in activity, he/she may be considered in disadvantage for the performance of activities viewed as normal given his/her age, sex and dominant socio-cultural factors" (Article 2, para.1).

In 1986, Portugal joined the European Union and between 1986 and 2006, Portugal received significant funds from the European Social Fund to support initiatives aimed at promoting equality of opportunities in vocational training and employment for disadvantaged groups, including people with disabilities. The availability of such funds boosted the development of disability service providers, mostly in the form of vocational training services for people with disabilities. The key players in this new industry continued to be disability organisations. The numbers of disability organisation grew quickly and exponentially, as well as those of beneficiaries. Most of the organisations were based on a charitable approach to disability and their services further segregated disabled people from mainstream services and reinforced the medical deficit-based model of disability (Pinto 2011a, 121; Fontes 2009; Pinto 2012, 142–46).

The first tendencies towards a citizenship approach only emerged after 2000, due to international pressure: Portugal being part of the United Nations and European Union social policies needed to be adjusted. As a consequence anti-discrimination legislation for people with disabilities was implemented in 2006 (law 46/2006, 28th August 2006) and the National Action Plan for the Integration of People with Disabilities 2006-2009[111] came into force. In 2010, a National Disability Strategy

[110] Law 9/89 of 2 May 1989

[111] Plano de Acção para a Integração das Pessoas com Deficiências ou Incapacidade

(*Estratégia Nacional para a Deficiência* 2011-2013 - ENDEF) was launched[112]. The National Institute for Rehabilitation (*Instituto Nacional para a Reabilitação (INR, I.P).*), however, concluded only 101 of the 133 measures (Instituto Nacional para a Reabilitação 2014). Although the Portuguese Government has established the Commission of ENDEF II[113]in 2012, in order to develop and submit a proposal for the National Strategy 2014-2020 (ENDEF II), the new disability policy has not been adopted yet. Consequently, since 2013, there is no coherent disability policy in place. In sum, as researchers have found Portugal has produced advanced legislation but often it only serves to satisfy European directives lacking full implementation in practice (Loja, Costa, and Menezes 2011, 576). Moreover, as Santos outlines, distinctive in the Portuguese case is the quality and degree of the discrepancy between the law and its implementation in practice (Santos 1991, 19). How this affects employment policies for disabled people is shown in the following section.

6.2 Employment policies and the legal framework for people with disabilities in Portugal

> "The key challenge faced by persons with disabilities is full inclusion in society, in general, and in particular in the labour market; without economic independence it is very difficult to achieve social independence" (Portuguese Ombudsman 2016, 16).

As outlined above, due to the late development of the Portuguese social security system, disability has until recently been conceptualised in a charitable perspective (Fontes 2014; Pinto 2011a; Fontes, Martins, and Hespanha 2014). Up until today, the strong welfare society serves as a compensation mechanism for the shortages of the Portuguese welfare state (Santos 1991). As a result, disability related benefits have been and remain very low. The table below shows the disability related benefits that are available to adults living with a disability in Portugal.

[112] Resolution of the Council of Ministers Nr. 97/2010 of 14th of December

[113] Government Order No.15432/2012; of December 4

Table 7: Disability related benefits in Portugal

Social Benefits	Monthly amount provided
Social Benefit to Inclusion [114] (since 1st October 2017) For people with a degree of disability of at least 60 % and who are older than 18 years.	Degree of disability between 60 % and 80 %: up to 269,08 € (in 2018) depending on: • Degree of disability • Other incomes Degree of disability 80% or more: 269,08 € (regardless of other income)
Dependency allowance For people who need support with daily needs and who are not working and receive a pension of less than 600 €	103,51 € (1st degree of dependency) 186,31 € (2nd degree of dependency)[115]

Source: http://www.seg-social.pt [date of access: 24/09/2018]

Furthermore, to be entitled to disability related benefits, the disabled person needs to be examined by a 'medical committee'. The National List of Incapacities (Decree-law 341/93) serves as a reference framework. The list resembles the AMA (American Medical Association) Guide and is organised around diagnostic categories, such as neurology and reproductive system[116]. The 'coefficient of incapacity' that is issued depends on a medical diagnosis. Although the observing doctor can adjust the coefficient, adjustments need to be explained. Depending on the work, the examined person usually does or has been doing the degree of disability/invalidity (e.g. 80 %) is

[114] *Prestação Social para a Inclusão*. The Social benefit to inclusion replaces the former unconditional *Lifetime Monthly Allowance* (Subsídio mensal vitalício) which was provided to people with a disability who were older than 24 years and who were not able to provide a living through work. It also replaces the former *Invalidity Pension* (pensão de invalidez) and the Social Invalidity Pension (pensão social de invalidez). For more information see http://www.seg-social.pt/prestacao-social-para-a-inclusao [date of access: 17/02/2018].

[115] 1.º degree of dependency – people who are not able to fulfil basic necessities on a daily basis (personal hygiene, nurture themselves, movement);
2.º degree of disability – people who on top of the first degree of disability, are confined to bed or who have a severe dementia.

[116] The national list of Incapacity is available online at http://www.spot.pt/media/64876/tabela_nacional_incapacidades.pdf [date of access: 09/09/2017]

determined. Although the National List of Incapacities is a binding law, it leaves plenty of scope for interpretation and therefore gives power to the medical expert (European Commission 2002, 138–40).

Until October 2017, an Invalidity pension (*pensão de invalidez*) was paid to people who cannot work due to the severity of their disability or who need care and supervision. The amount of the invalidity pension depended on the number of previous working years and the total contributions to social security payments[117]. Disabled people who received the invalidity pension lost their entitlement if they started working and gained an income from work. Only lately this procedure changed. Up until the 30th September 2017, people with disabilities who were older than 24 years and who had never worked and who were not able to provide a living through work received a non-contributory Lifetime Monthly Allowance (Subsídio mensal vitalício). In 2017, the Lifetime Monthly Allowance was 177,64 €/month (Direção-Geral da Segurança Social 2017). On October 1st 2017, the newly introduced Social Benefit to Inclusion (Prestação Social para a Inclusão) replaced the former Lifetime Monthly Allowance and the Invalidity Pension (*pensão de invalidez*). For people with a degree of incapacity that is 80% or more a monthly benefit of 264,32€ (in 2017) is paid regardless of other sources of incomes, such as income from work related activities. For disabled people who have a degree of incapacity between 60% and 80%, the Social Benefit to Inclusion depends on other means of income. The entitlement depends also on the age of the recipient. Only people who are at least 18 years old and who have not reached legal retirement age yet are entitled to the Social Benefit to Inclusion. A recent study has shown that despite the low amounts of the disability-related benefits, for many persons with disabilities these social benefits are the main/only source of income (Portugal et al. 2010). In the following it is shown that the specific measures which are in place to support the employment of disabled people are limited. Before focusing on Decree-law 290/2009 of 12th October, which was implemented in 2009 and has since then determined the specific measures available to people with disabilities in the area of employment and professional qualification, it will be shown how the promotion of

[117] For further information see http://www.seg-social.pt/pensao-de-invalidez [date of access: 02/07/2017]

employment is, at least in the law, guided by the overarching principle of non-discrimination.

Non-discrimination in employment

In contrast to the German constitution, the equality clause (§ 13) of the Portuguese Constitution[118] does not explicitly mention disability as a ground of discrimination[119]. The Constitution does consider disability only in Article 63 "Social Security and Solidarity" and Article 71 "Disabled Citizens" which guarantees persons with disabilities the rights and duties of the Constitution (section 1) but also puts an emphasis on the prevention, treatment and rehabilitation of disabled people (section 2). In Portugal, anti-discrimination legislation for persons with disabilities was implemented in 2006[120]. Article 5 of the Anti-discrimination legislation addresses the issue of discrimination in work and employment. Referring to the Labour Code, Article 5 prohibits discrimination of both, direct and indirect nature in the workplace, including the hiring or termination process. Under the legislation employers are also required to address discrimination at the workplace by implementing reasonable accommodation measures (Article 84). The anti-discrimination law offers individuals, or disability organisations on their behalf, the opportunity to submit a complaint if they are subject to discriminatory practices. The burden of proof remains with the plaintiff who needs to substantiate his/her complaint. The graph below shows the development of the complaints received by the National Institute of Rehabilitation (INR, I.P.) [121].

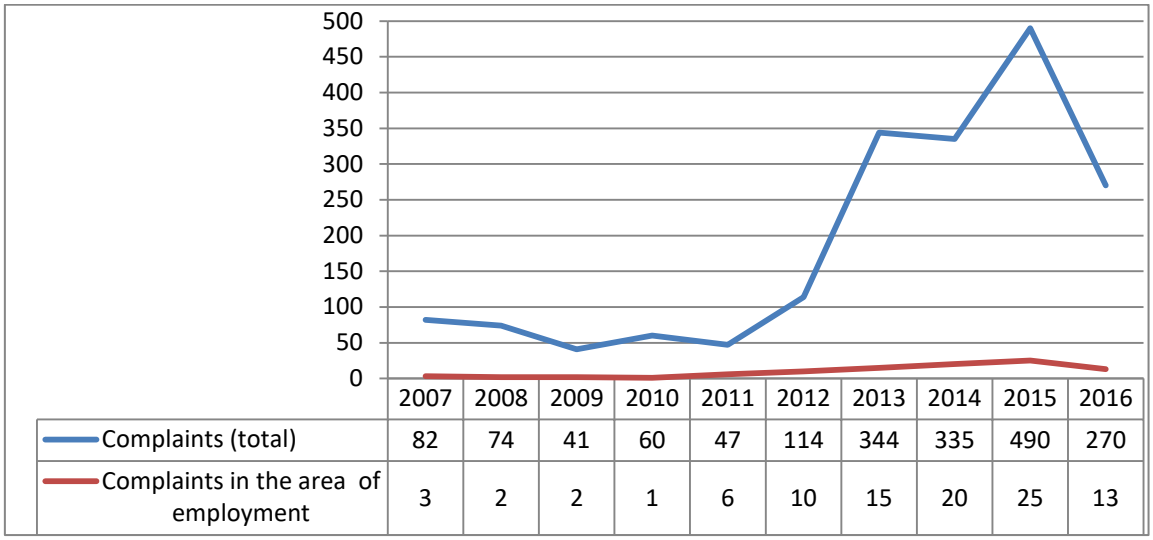
[118] The latest amendment of the Portuguese Constitution occurred in 2005. The Portuguese Constitution is available online at http://www.parlamento.pt/Legislacao/Paginas/ConstituicaoRepublicaPortuguesa.aspx [date of access 11/02/2018].

[119] However, scholars have suggested that the clause applies to people with disabilities as well, since the grounds enunciated are not supposed to be exhaustive (Pinto and Teixeira 2012a, 46).

[120] Law 46/2006, 28th August, available online at http://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---ilo_aids/documents/legaldocument/wcms_127489.pdf [date of access 11/02/2018].

[121] The *Instituto Nacional para a Reabilitação* (INR) is the institution that receives the complaints. The INR is publishing an annual report, that is available online at http://www.inr.pt/content/1/1185/lei-da-nao-discriminacao [date of access 25/09/2018]. Latest figures are available from 2016.

Graph 19: Complaints received under the Anti-Discrimination law, Portugal



	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
Complaints (total)	82	74	41	60	47	114	344	335	490	270
Complaints in the area of employment	3	2	2	1	6	10	15	20	25	13

Source: INR.IP. Relatório Annual. 2007-2016.

The graph shows that after a high increase between 2011 and 2015, the number of complaints dropped between 2016 and 2015. In 2015, 502 complaints were received, 25 of them addressing the area of employment. These amounts marked the maximum numbers received up until then. In 2016, however, only 270 complaints (13 addressing the area of employment) were filed with the National Institute of Rehabilitation. The National Institute of Rehabilitation outlines in its reports that it is often difficult to prove that disability is the cause for discriminatory attitudes. As a result many cases are dropped due to the lack of evidence (Instituto Nacional para a Reabilitação 2017, 10). Due to the difficulty of proof, the ADP (Associação Portuguesa de Deficientes) argues that the anti-discrimination law has zero impact on the employment situation of disabled people (Associação Portuguesa de Deficientes 2012, 8).

Additionally to the specific anti-discrimination legislation, the principle of non-discrimination in work and employment is promoted and enforced through the Portuguese Labour Code. The Labour Code[122], which was the Portuguese translation of the European Employment Equality Framework Directive (Council Directive 2000/78/EC) provides any employee or job candidate the right not to be directly or indirectly discriminated against, based on several personal characteristics, including

[122] The Labour Code was approved by law 7/2009 of 12 February and amended 10 times since its initial implementation. The last amended occurred by law 28/2016 of 23 August. All amendments can be found online at http://cite.gov.pt/pt/legis/CodTrab_indice.html [date of access 07/07/2017]

disability, reduced working capacity or chronic disease (Article 24(1)). This anti-discrimination provision applies to all stages of employment, including (1) the recruitment, selection and hiring processes; (2) access to vocational guidance, training and retraining; (3) payment and other reward systems as well as career development or dismissal; and (4) participation in collective bargaining structures. Under the Labour Code employers are required to post in the job advertisement a list with the rights and duties related to equality and non-discrimination. Under article 27 of the Labour Code positive discrimination, in the form of timely limited legislative measures to benefit a discriminated group and correct a situation of inequality, is allowed. Furthermore, article 85 specifically refers to workers with disabilities or chronic diseases; the law states that these workers have the same rights and duties as all other 'regular' workers, and affirms the duty of the State to stimulate and support employers in their hiring and professional rehabilitation. In addition, employers shall take all adequate measures to guarantee that these workers have the rights of getting access to a job and to be able to advance in a career, unless such measures costs are considered disproportionate (Article 86(1)). Considering that the State must support the employer within this process (Article 86(2)), the situation of disproportionate costs is not considered a plausible excuse whenever State aid is available (Article 86(3)). Under the Labour Code, special conditions apply to workers with disabilities or chronic diseases; (1) they are exempt from providing work in specially organised working schedules or during the night, whenever such work may be harmful for their health or safety (Article 87, Labour Code), and they shall also be exempt from overtime work (Article 88, Labour Code). In the subsection related to 'workers with reduced working capacity' the law states that employers must enable working conditions to these workers, namely by providing workplace adjustments, and promoting adequate vocational training and professional development (Article 84(1)). Once more, it is outlined that these accommodation measures must be supported by the State (Article 84(2)).

Employment support for people with disabilities

In 2009, decree-law 290/2009 was passed determining that employment advice and support services must be provided to promote the employment of disabled

people. Since its first implementation the law was amended several times[123]. The Institute for Employment and Vocational Training is the responsible public agency which works in cooperation with the Employment Centres (*Centros de Emprego*) - local structures of the IEFP- or Training[124] and Resource Centres (*Centros de Recursos*) - private non-profit organisations which are accredited by the IEFP and which have an expertise in working with/for people with disabilities. The IEFP funds the following measures:

- Support to integrate, sustain and reintegrate disabled people in the labour market. The support is provided through four specific measures: 1) information, assessment and guidance to qualification and employment; 2) placement support; 3) post placement support; 4) workplace adjustments and removal of architectural barriers. Private non-profit organisations are the main providers of these services.

- Support to acquire, adapt or repair assistive devices which are necessary to provide an access to vocational training or to obtain and sustain an employment and a career path. This support is integrated in the system of the system of allocation of support products (SAPA).

- Supported employment measures, which includes the following types of support: 1) traineeships for integration; 2) employment integration contracts; 3) sheltered employment; 4) supported employment in the open labour market (enclaves).

- Inclusive Employer Award; an award that honours employers that have shown inclusive practices considering people with disabilities.

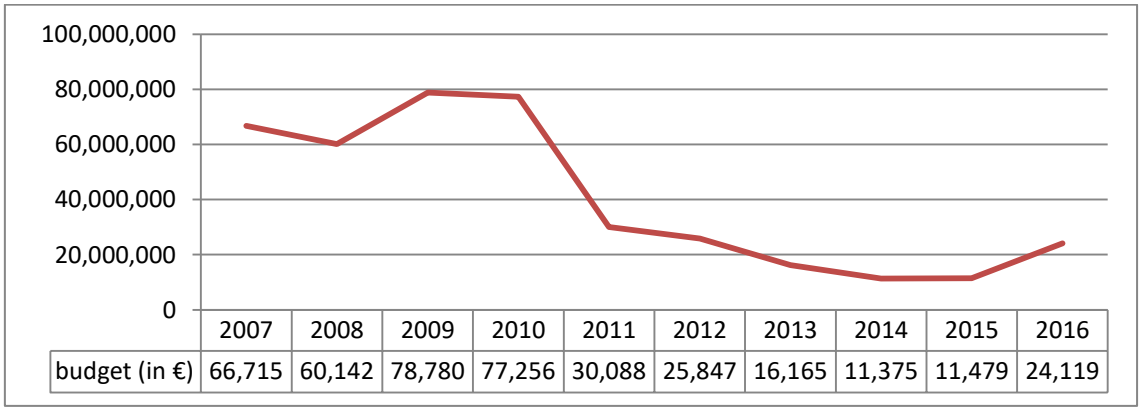
The annual financial report of the IEFP outlines that prior to 2009 there was a slight increase of both expenses and disabled people participating in employment support

[123] Most recently in 2015 by decree-law 108/2015 of June 17 and in 2013 by decree-law 131/2013 of September 11. For example, in 2013 financial supports that previously were only available to private employers were extended to public employers (except those who are part of the economic sector under the direct administration of the State).

[124] Centros de Formaçao professional de gestão participada

programmes. As for other citizens, the support for disabled people decreased from 2008 onwards, when austerity measures began to be implemented (Pinto and Teixeira 2012a). In the case of measures financed through the IEFP, after 2009 the annual budget dropped from 78.780.255 € in 2009 to 11.479.487 € in 2015, which was mainly caused by the drastic reduction of training hours (see below). A small increase occurred in 2016, when the budget increased to 24.119.697 € (graph 20). Nevertheless, at the same time, the number of disabled beneficiaries nearly doubled between 2007 and 2016 from 12158 to 23684 (graph 21).

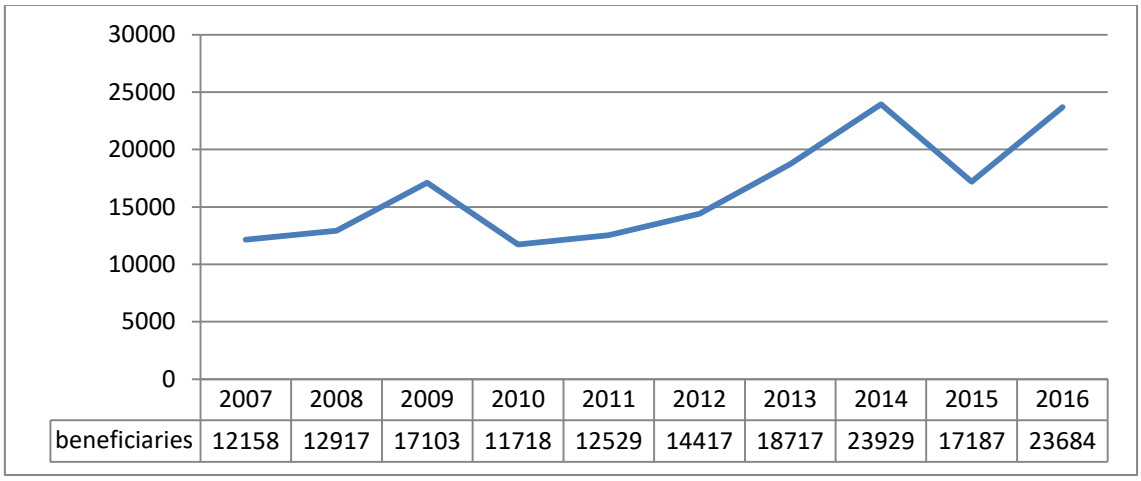
Graph 20: Professional/Vocational Rehabilitation for disabled people, public spending, Portugal



	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
budget (in €)	66,715	60,142	78,780	77,256	30,088	25,847	16,165	11,375	11,479	24,119

Source IEFP: Relatório de Execução Física e Financeira 2009-2016

Graph 21: Professional/Vocational Rehabilitation for disabled people, number of beneficiaries, Portugal



	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
beneficiaries	12158	12917	17103	11718	12529	14417	18717	23929	17187	23684

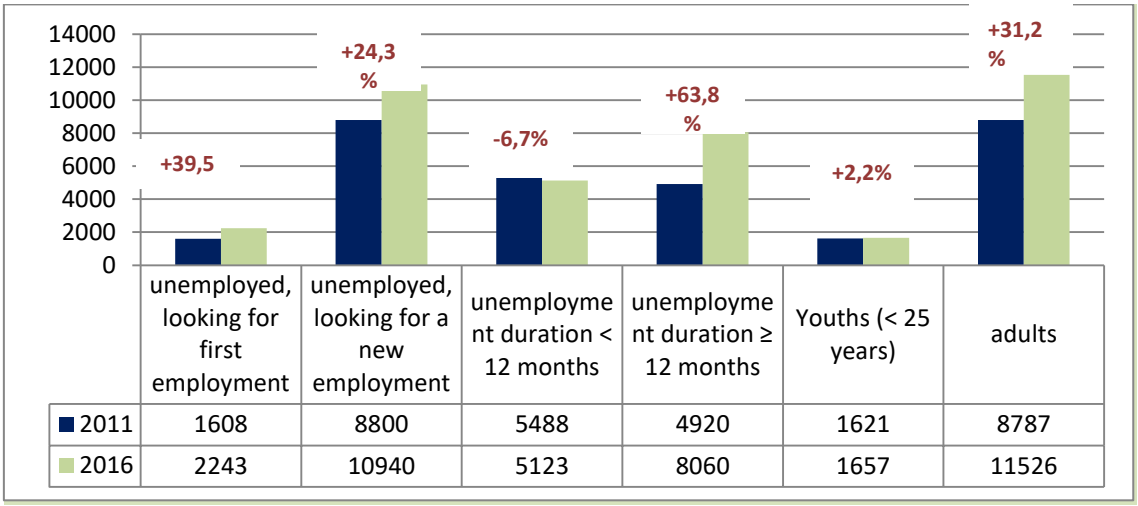
Source IEFP: Relatório de Execução Física e Financeira 2009-2016

The rising numbers of beneficiaries came along with the rising numbers of disabled people who are registered at the National Employment and Vocational Training Institute. In December 2016, 13183 persons with disabilities were registered as

unemployed at the Employment and Vocational Training Institute[125] (see graph 18). The registration at the National Employment and Vocational Training Institute is a necessary requirement to have access to the measures under Decree-law 290/2009.

Graph 22 presents more details about the group of persons with disabilities who are registered as unemployed.

Graph 22: Persons with disabilities who are registered as unemployed at the IEFP, by the unemployment type and age group, 2011 and 2016



	unemployed, looking for first employment	unemployed, looking for a new employment	unemployment duration < 12 months	unemployment duration ≥ 12 months	Youths (< 25 years)	adults
2011	1608	8800	5488	4920	1621	8787
2016	2243	10940	5123	8060	1657	11526

Source: Pinto e Pinto 2017, 36

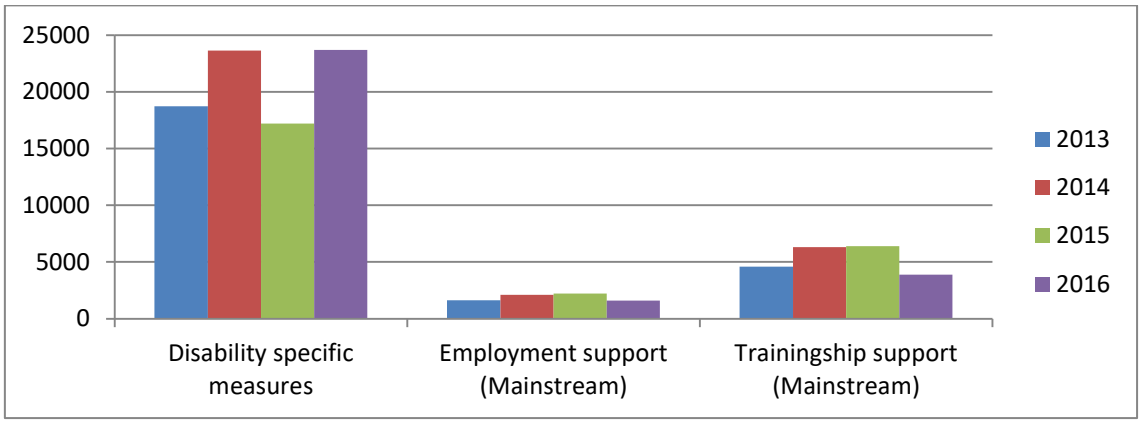
The figures indicate that the increase among people looking for a first employment was higher (39,5%) than the rise among people looking for a new employment (24,3%). At the same time, the numbers show that between 2011 and 2016 in particular long term employment (registered as unemployed for at least 12 months) has increased (+ 63,8%) while the short term unemployment has slightly decreased by 6,7 %. The numbers of adults registered as unemployed (+31,2%) rose more than the numbers of youths (+2,2 %). As the Human Rights Indicators report outlines these figures could reflect the rise of internships and non-permanent employment opportunities for people with disabilities (Pinto and Pinto 2017, 33).

The qualification programme

[125] These official numbers of the IEFP do not represent the real situation as many people with disabilities do not register at the unemployment institute.

Besides the mainstream training scheme available to all people registered with the IEFP, people with disabilities have access to the disability-specific scheme. As the table below shows the majority of disabled people are accessing the measures under the specific employment regime. The figures of disabled people who access mainstream measures are low.

Graph 23: Number of people with disabilities who participate in employment support measures provided by the IEFP by type of support, 2013-2016



Source: Pinto e Pinto 2017, Pessoas com Deficiência em Portugal: Indicadores de Direitos Humanos 2017, p. 38

The specific support under Decree-law 290/2009[126] of 12 October implies that organisations and enterprises that offer training to people with disabilities can obtain financial support. The aim of the training is to increase the workability and other skills of the trainees to support their integration in the open labour market. The specific target group are persons with disabilities who have no school or professional qualification and people with disabilities (employed or unemployed) who want to improve their work skills. The trainees are supported by a monthly grant that depends on their professional qualification[127]. Prior to the implementation of the new legislation in 2009, the total number of training hours per trainee was 5800 hours. Decree-law 290/2009 of October 12 reduced the maximum financed period to 2900 hours of training for each person with disability (3600h in the case of students with

[126] The law has been amended by law 24/2011 of June 16, decree-law 131/2013 of September 11, and by the degree law 108/2015 of June 17.

[127] From a monthly grant up to 1 IAS (Qualification level 2 or lower) up to 1,65 IAS ((Qualification level 6, 7 or 8), in addition a food and transport allowance, as well as a contribution to a work accident insurance. Amount of IAS in 2015: 419,22 €.

learning disabilities, if the extension is properly justified). Although studies show that the reduction of the period of training had a negative impact on the outcome of this programme and that the rate of employment at the end of the training decreased significantly (Pinto and Teixeira 2012a, 6–7), the maximum amount of training was further reduced in 2015[128]. At the end of each training an official certificate is delivered. A continuing training programme is intended for those people with disabilities (employed or unemployed) who have already participated in an initial training and want to raise their professional qualifications further (or are required to do so by their employer). It is performed also by the vocational training centres and resource centres as well as by employers who want to increase the professional qualification of their employees[129].

As the ODDH parallel report shows there is a lack of information about the long term effects of these trainings and research has shown that even when people with a disability have found a good position and comply with the work requirements, they are often dismissed after the support period as employers replace them with other trainees (Disability and Human Rights Observatory 2015). As Pinto showed in her study, there is also a gendered pattern in access to the Portuguese support system. Women with disabilities are underrepresented in the regular system of employment and education, and they seem to benefit less from the specialised services of vocational training, rehabilitation as well as from disability-related social supports when compared to men with disabilities (Pinto 2012). Overall there is only little information available about the quality and outcome of the integration, reintegration and maintenance support services. As disability advocacy organisations claim, there is a risk that vocational training often only present another form of income for disability-related associations and institutions. A stronger supervision and evaluation of these programmes is thus required (Autistic Minority International 2016).

Although limited in scope, considering the numbers of disabled people attending mainstream measure (see graph above), people with disabilities are specifically

[128] Decree-law 108/2015 of June 17

[129] Ordinance 8376-B/2015, of 30 July amended through Ordinance 9251/2016, of July 20

mentioned as a target groups in recently introduced general employment measures, such the Portuguese Youth Guarantee Programme(Garantia Jovem)[130]. In April 2013 the European Council Recommendation to establish a Youth Guarantee was adopted to tackle the high levels of youth unemployment prevalent across the European Union. The aims of the Youth Guarantee are to ensure that all young people receive a good-quality offer of a job, apprenticeship, traineeship, or continued education within four months of leaving formal education or becoming unemployed (European Commission 2018). In Portugal, the Youth Guarantee Programme was implemented in March 2014[131] and enacted through Ordinance 149/2014 of 24 July[132]. The new scheme allows a reduction of the social security contribution to employers who hire long-term unemployed youth – including youth with disabilities, aged between 18-30 years. This Ordinance implemented also an Employer Stimulus programme (Estímulo Emprego); Employers get financial support from the IEFP if they employ a long-term unemployed youth. In case of a fixed term contract the financial support equals 80% of the IAS[133] multiplied by half of the entire number of months of the contract's duration (maximum support period six months). This means that, if an employer offers a six month contract, the support by the IEFP is provided for 3 months. In case of hiring unemployed disabled persons the financial support equals 100% of the IAS. If a permanent contract is provided the financial support equals 110% of the IAS for 12 months. Furthermore, a company can claim tax reductions (payments for social security) for the disabled employees: instead of paying 23,75% of the gross salary of the employee, the company only pays 11,9% for workers with disabilities.

Financial incentives/workplace adaptations[134]

Employers who hire a person with disability, can also obtain financial assistance from the State by receiving compensation for the costs of workplace adaptations and

[130] https://www.garantiajovem.pt/ [date of access: 15/07/2017]

[131] Resolution of the Council of Ministers No. 104/2013 of 19 December

[132] In the meantime, the legislation was replaced by Ordinance 131/2017 of 7 April.

[133] The IAS is the standard rate for social support; in 2018 it is: 428,90€.

[134] Adaptação de Postos de Trabalho/Eliminação Barreiras Arquitectónicas

the elimination of architectural barriers, as well as social security exemptions and reductions. Under the initial legislation of 2009, financial assistance for workplace adaptations and the removal of architectural barriers were only available to private employers. Decree-law 131/2013 of 11 September extended the financial supports to public entities that are not part of the State administration. According to Article 33, the IEFP can provide financial assistance for necessary workplace adaptations when: a) a person with disability is registered at the employment centre as unemployed or is looking for a first job, and s/he is offered a permanent employment contract or a one-year initial employment contract; or b) an employee acquires a disability whilst working. However, in cases in which impairments result from a work-related accident or an occupational disease, funding is not available (article 33 (2)). The maximum incentive equals 16 times the IAS (Social Support Index, 419,22 € in 2015) for each person, but cannot exceed 50% of the total adaptation costs. In cases in which the employment contracts terminates prior to the prospective termination date or during the first three years in case of a permanent contract, either by the employer's initiative or by the employee's initiative but for reasons related to the employer, the employer has to return the amount received for workplace adaptations (Decree-law 108/2015, Art. 36).

Considering the number of people supported by this measure, the measure has only had very little impact in practice (see table 9). After 2009, the amount of people who were supported by workplace adaptations dropped significantly and remained at a very low level.

Table 8: Workplace adaptations/Elimination of architectural barriers

		2009	2010	2011	2012	2013	2014	2015	2016
Workplace adaptations/ Elimination of architectural barriers	**beneficiaries**	546	66	3	1	3	3	2	10
	budget (in €)	3.371.824.65	1.040.597.44	69.994.66	21.006.79	17.150.83	0.00	2.376.19	8.389.89

Source: IEFP Relatório de Execução Fisica e Financeira 2009-2016 available online at https://www.iefp.pt/estatisticas

Provision of technical devices[135]

The IEFP compensates the cost of workplace adaptations if they are not covered by the health system or private insurance. If they are covered by other systems, the IEFP compensates a part of the costs. Furthermore, the IEFP supports products that comply with the following requirements: 1) are needed to access or attend vocational training; 2) are complementary to other measures to support employment and training; 3) do not constitute an adaptation of the job or training equipment that should be made available, respectively, by the employer or the training entity; 4) are at the cheapest possible option. In the latest legislative change (decree-law 108/2015 of 17 June) people who obtain financial support for assistive for the workplace are explicitly mentioned as beneficiaries of employments support measures. In 2015, the IEFP supported the purchase or reparation of assistive devices for a total of 217 people with disabilities – 83 of them were female and 134 were male (Instituto Nacional para a Reabilitação 2015, 42). The majority of beneficiaries - 119 beneficiaries or 54,8% - had a high school or university degree (Instituto Nacional para a Reabilitação 2015, 44). In total 495 products were purchased and the total cost summed up to 1.566.271,83 € (Instituto Nacional para a Reabilitação 2015, 45). The majority of assistive devices (266) addressed physical body functions that are related to body movements, followed by assistive devices for blind and partially sighted people (161 devices) (Instituto Nacional para a Reabilitação 2015, 46). Research shows that the provision of assistive devices is an area which has been severely affected by government cuts under austerity. At the same time the process of obtaining assistive devices is highly bureaucratic and it takes a long time to have them approved (Pinto and Teixeira 2012b). In cases in which workplace adaptations and assistive devices are not sufficient to facilitate the inclusion of disabled people in the open labour market, the supported employment regime provides measures aiming to achieve this goal.

[135] Sistema de Atribuição de Produtos de Apoio (SAPA)

Supported employment regime

Supported employment aims to enable people with disabilities to develop personal and professional skills to facilitate their transition to a 'regular work regime' and includes the following measures[136]:

(1) Internships/Traineeships (Estágios de inserção)(§§ 40-41), that aim to provide practical training (maximum 12 months);

(2) Employment Insertion Contracts (Contrato Emprego-Inserção) (§§ 42-44) to develop socially useful activities and to strengthen social and personal skills in order to improve their employability and personal autonomy (maximum 12 months);

(3) Sheltered Employment Centres (Centro de Emprego protegido) (§§ 45-53);

(4) Supported Employment Contract in the Open Labour Market (Contrato de emprego apoiado em mercado aberto de trabalho) (§§ 54-58), this measure includes the creation of an enclave in the open labour market to integrate one or a group of workers with disabilities in the "regular" work environment.

Sheltered employment centres

In its concluding comments, the UN Committee asked Portugal to abolish its segregated working environments and to review the legislation from a human rights perspective. Sheltered employment centres in Portugal are run by public entities which are not under the direct regime of the State administration and by private non-for profit organisations. The sheltered employment centres are under the guardianship of the IEFP. Standard labour laws apply in Portuguese sheltered workshops. Regarding to the Decree-law 290/2009 of 12th October, the target group of sheltered employment centres are people with disabilities who have a reduced working capacity which is

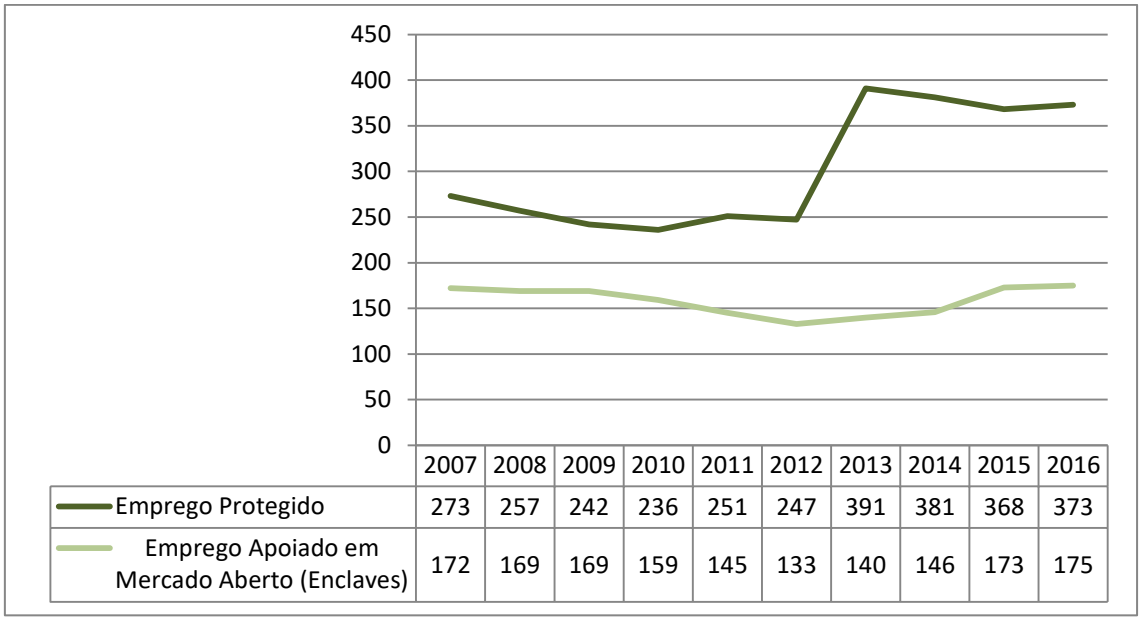
[136] Degree law 108/2015 of June 17

between 30% and 75% compared to a non-disabled person in the same professional function (§ 46). The IEFP is co-funding the building, the establishment and the equipment of sheltered workshops, as well as the wages of the workers, their social security contributions and necessary workplace adaptations. Sheltered employment centres aim to provide disabled people with a professional activity and the possibility of training and / or vocational improvement to support their transition to the open labour market, wherever this is possible. For each worker, the wages are meant to be set in the same proportion of his/her work capacity, taking into account the salary that a regular worker would get for the same work. Wages can, however, never be set below the minimum wage. Only during the initial period of apprenticeship (maximum 9 months) the disabled worker receives 70% of the minimum salary[137]. The first sheltered workshop in Portugal opened in 1988.

There is only little information available about the situation of people working in sheltered workshops and no information about the transition rate into the open labour market. Although by law the work in sheltered workshops is meant to be temporary, as Visier outlines the career, advancement and promotion prospects in sheltered workshops in Portugal were considered "very limited" (Visier 1998, 356). Compared to Germany, however, the number of disabled people working in sheltered workshops is very low (see graph 24): in 2016, 373 persons with disability worked in sheltered workshops and 175 worked in enclaves in the open labour market. At the same, there were 310.033 people working in sheltered settings in Germany in 2017.

[137] Decree-law 108/2015 and decree-law 40/83, of January 25 on Sheltered Employment, http://www.inr.pt/bibliopac/diplomas/dl_40_83.htm#_ftn1 [date of access: 29/06/2018]

Graph 24: Sheltered employment in sheltered workshops and sheltered employment in enclaves, Portugal



	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
Emprego Protegido	273	257	242	236	251	247	391	381	368	373
Emprego Apoiado em Mercado Aberto (Enclaves)	172	169	169	159	145	133	140	146	173	175

Source: IEFP

In a recent study, Sebrechts outlines that although Portuguese policy documents frame the participation of co-workers (disabled people working in sheltered workshops) in a language of productivity and personal responsibility (the aim of the work in sheltered workshop is to enhance individual capacities and individual autonomy), the reality is different. In her study, she shows that professionals in sheltered workshops not only focus on the improvement of work-related skills, but also aim to educate the disabled co-workers into being and becoming a ´good human being´. In doing so, professionals act in many situations as “teachers” or “parents”. In her research, she witnessed shared punishments, when co-workers did not obey the rules or instructions as well as a strong hierarchy and inequalities between professionals and disabled co-workers. Such practices increase the risk of humiliation and co-workers who enter the labour market from a sheltered employment act more likely as a ‘humble’ worker, rather than as self-confident and autonomous worker (Sebrechts forthcoming thesis).

Supported employment in the open labour market

Article 54 of Decree-law 108/2015, of 17 June recognises the measure of 'Supported Employment in the Open Labour Market’ as a professional activity of

persons with disabilities in a mainstream working environment. The measure applies to people with a disability who have workability between 30% and 90%[138] compared to a non-disabled person working in a similar position. Employers providing Supported Employment in the Open Labour Market can request co-funding of expenses with wages and social security contributions (Art. 57). Furthermore, they can receive financial support, for instance, to cover transportation costs or meal allowances for those workers (Art. 44). The supported employment period may last up to 36 months and can be extended further if fundamental reasons exist (Art. 27, Decree-law 108/2015). Although Portugal was one of the first countries that addressed disabled people as a target group of supported employment (Associação Portuguesa de Emprego Apoiado 2005, 19), the measure is not well known amongst employers (Costa 2015).

Inclusive employer brand/public award system

The Inclusive Employer Brand (Marca Entidade Empregadora Inclusiva) is delivered every two years to raise awareness among employers and distinguish best practices regarding the employment of persons with disabilities. Decree-law 108/2015 of June 17 amended the Inclusive Employer Brand allocated as a public award (Prémio de Mérito) to honour and reward especially successful cases of employers that have established open and inclusive practices for persons with disabilities in the areas of recruitment, retention, accessibility and community services (Art. 78).

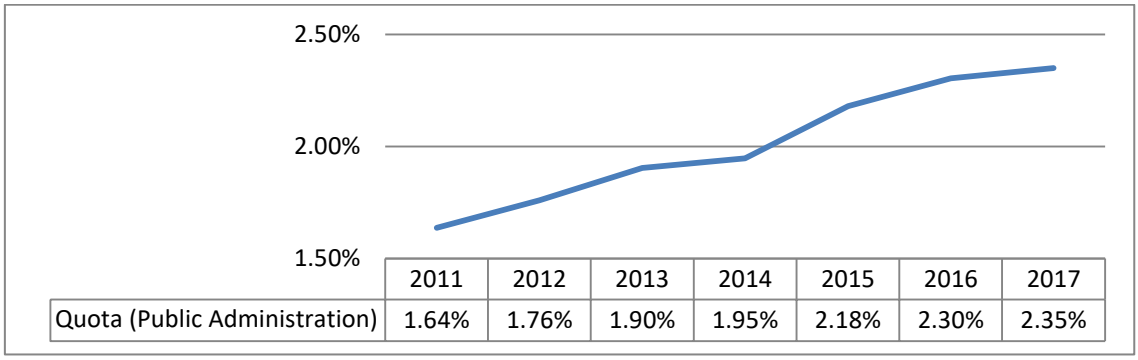
Employment quota

In addition to Decree-law 290/2009 and in order to promote the professional integration of persons with disabilities within Public Administration, Decree-law 29/2001 of 3 February established a mandatory quota for the public sector. The law states that in all recruitment processes in the public sector, that involve ten or more vacancies, a 5% quota should be reserved for persons with disabilities (with an incapacity level of at least 60%); when recruitment involves between three and nine vacancies, one of them should be allocated to a person with disabilities; and when the

[138] Prior to the latest amendment in 2015, the measure only applied to people with incapacity levels between 30% and 75%.

recruitment process involves one or two vacancies, the candidate with a disability should have priority. Disabled applicants should only be hired preferentially, if they present similar qualifications. At the present moment the quota law only applies to the public sector, there is no such obligation in place for the private employers. The graph below shows that there has been a steady increase of the quota in recent years. Nevertheless, the quota is still far below 5 %: In 2017 it was at 2,35 %.

Graph 25: Quota in Public Administration, 2011-2017, Portugal



	2011	2012	2013	2014	2015	2016	2017
Quota (Public Administration)	1.64%	1.76%	1.90%	1.95%	2.18%	2.30%	2.35%

Source: DGAEP-SIOE. 2017. Boletim estatístico do emprego público (BOEP)[139], N.º 17, December 2017

The available data reveals that the increase has been caused by a steady but small growth of workers with a disability and a decrease of total numbers of employers at the same time. There is no data available that specifies the age of the disabled employers or the years they have been working in public administration. Therefore the data does not disclose if the increase occurred due to demographic changes within the workforce and the overall higher prevalence of disability among older people.

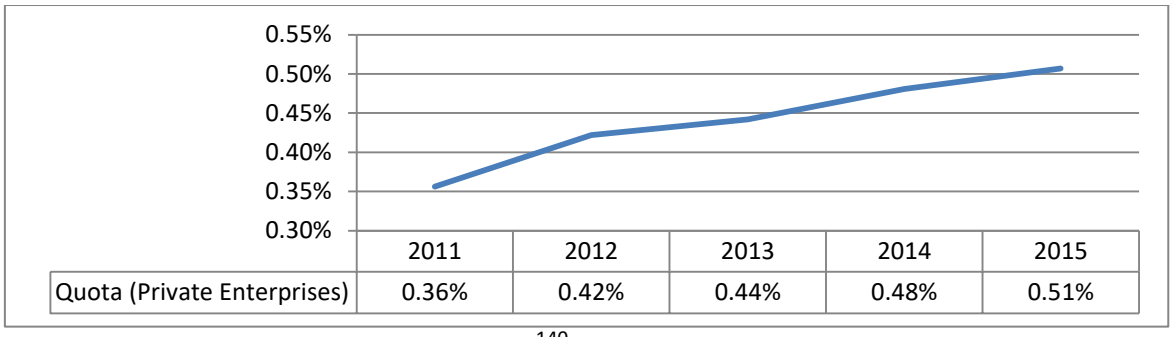
A study conducted in 2008, however, showed that more than 40 % of the public servants with a disability had an impairment that was related to cancer and that most of them might have already been employed in the public sector before they acquired their disability. The study concludes that the quota law has limited effects on the admission procedure (Anjos and Rando 2009). The fact that due to the austerity measures the recruitment for public administration has been allowed only under exceptional conditions, and that in recent years very few recruitment processes included more than one or two vacancies, also suggests that the quota is mainly

[139] available online at https://www.dgaep.gov.pt/index.cfm?OBJID=C0F56E62-5381-4271-B010-37ECE5B31017 [date of access 11/02/2018]

increased by public servants who acquire a disability during their professional career. In contrast to other countries, such as Germany, no penalty does apply when public administration bodies do not fulfil their obligation under the quota law. According to the ODDH Parallel Report 2015, the quota law remains poorly enforced (Disability and Human Rights Observatory 2015, 33) and the ADP describes the measure as insufficient (Associação Portuguesa de Deficientes 2012, 10).

The annual Social Reports of the Office of Strategy and Planning in the Ministry of Labour and Social Solidarity provide data on disabled employers in the private sector. The data shows that the percentage of disabled workers in the private sector is very low. In 2015, only 10.210 workers with a disability were employed in the public sector. This presents a proportion of 0,51 %. The graph below shows that the proportion has increased in recent years, yet it remains extremely low. An issue which needs to be paid attention to under the human rights framework.

Graph 26: Propotion of workers with disabilities in private enterprises, 2011-2015, Portugal



	2011	2012	2013	2014	2015
Quota (Private Enterprises)	0.36%	0.42%	0.44%	0.48%	0.51%

Source: GEP – MTSSS. 2017. Balanço social, 2011-2015[140]

6.3 The UN Convention status in Portugal

The Convention on the Rights of Persons with Disabilities and its Optional Protocol was signed on 30th March 2007 and ratified on 15th July 2009, through Decree 71/2009 published in the official journal on 30th July 2009. The ratification followed approval by the Portuguese Parliament, through Resolution 56/2009 of 7 May, also published in the official journal on 30 July 2009. The ratification act was deposited with the

[140] available online at http://www.gep.msess.gov.pt/estatistica/gerais/bs.html [date of access 11/02/2018]

Secretary General of the UN on 23 September 2009 and therefore, in accordance with Art. 45(2), the Convention entered into force in Portugal on the 23 October 2009. As Germany, Portugal has not presented any declarations, reservations or objections in relation to the UN CRPD and its Optional Protocol.

The National Institute for Rehabilitation (INR, I.P), which is a public body located under the authority of the Ministry of Solidarity and Social Affairs, is the focal point for disability policy and the implementation of the Convention. Its mission is to ensure the implementation, design and coordination of national policies aimed at promoting the rights of persons with disabilities. The National Institute for Rehabilitation is the body that coordinates national policies aimed at promoting the rights of persons with disabilities, including the right to work and employment. Furthermore, the Directorate-General of Foreign Policy (within the Ministry of Foreign Affairs) and the Office of Strategy and Planning (within the Ministry of Solidarity and Social Security) have been designated as governmental coordination mechanisms to facilitate action within government on the implementation and monitoring of the Convention on the Rights of Person with Disabilities. Decree-law 126/2011 of 29th December created the new National Council for the Policies of Solidarity, Charity, Family, Rehabilitation and Social Security as a broad consultative body of the Ministry of Solidarity and Social Affairs that also addresses disability issues. The new National Council replaced the former Council for the Rehabilitation and Integration of Persons with disabilities.

In Portugal, the independent monitoring mechanism was established by the Resolution of the Council of Ministers No. 68/2014, of 21 November. The independent monitoring body is composed of ten representatives from public entities and civil society organisations: one member of the Parliament, one member of the Ombudsman, one member of the Human Rights National Committee, one member of the Disability Commission, one person of renowned merit from the academia and members of five NGOs working with disability issues. The functioning of the independent monitoring mechanism is, however, restraint due to a lack of adequate funding (Esquerda 2017; Committee on the Rights of Persons with Disabilities 2016, 10).

Official reporting/shadow reporting

The first official country report was due in 2011. Portugal submitted its first report on 8th August 2012. In regards to Article 27 – "Work and employment" the report outlines that the Employment and Vocational Training Institute (IEFP) (Instituto do Emprego e Formação Profissional) provides a number of instruments, resources and programmes to enhance the employability of persons with disabilities. In accordance with the Integration Plan for Persons with Disabilities or Impairments, diverse measures are to be adopted, such as a system of support to the creation of self-employment by persons with disabilities, the development of complementary training in entrepreneurship; the elimination of architectural barriers, among others. Considering disability data, the initial report outlines that the IEFP runs an information and data management system on employment, which registers data on all persons (including persons with disabilities) that attend the IEFP employment centres (Committee on the Rights of Persons with Disabilities 2012, 24–25; Disability and Human Rights Observatory 2015).

The List of Issues in relation to the initial report of Portugal was adopted by the pre-sessional working group at its fourth session (7-11 September 2015). In regard to "Work and employment" the working group requested, inter alia, to provide information on the means, resources and programmes available to the Employment and Vocational Training Institute to improve the employability of persons with disabilities and to provide information on measures being developed to eliminate discrimination and inequality in the employment and working conditions of persons with disabilities, in particular women with disabilities. The Committee on the Rights of Persons with Disabilities further stressed that an explanation was needed to outline the function of the so-called Occupational Activity Centres (CAOs). On December 10th 2015, Portugal submitted its reply to the List of Issues. In contrast to the initial report more detailed information on the nature of measures and programmes was provided. However, despite the officially registered numbers of disabled people in the IEFP employment and training services, no studies or information was provided about the practical effects of existing programmes, means and measures. In its concluding observations (20th May 2016) the Committee was still concerned about discrimination

and inequality in employment and about the work conditions that disabled people - in particular women - find themselves in. Further concerns were raised about the failure of the Labour Code to address and require reasonable accommodation within companies. The Committee was further concerned about the conditions of persons with disabilities in the Occupational Activity Centres.

The Committee therefore recommended that:

a) Portugal reviews its public- and private-sector labour legislation to bring it into line with the Convention and that it take measures to enforce the law and apply the stipulated penalties for non-compliance (in close consultation with organisations representing persons with disabilities).

b) Portugal abolishes segregated working environments, that it review the legislation regulating the Occupational Activity Centres from a human rights perspective to bring them into line with the Convention and that it makes efforts to promote access to the regular labour market for persons with intellectual disabilities and autism.

c) The State Party should promote corporate social responsibility in connection with the employment of persons with disabilities.

d) Portugal should also consider the links between article 27 of the Convention and target 8.5 of the Sustainable Development Goals, with a view to achieve full and productive employment and decent work for all women and men, including for persons with disabilities, and equal pay for work of equal value (Committee on the Rights of Persons with Disabilities 2016)

Since the initial report of Portugal was submitted further parallel reports have been submitted by the Disability and Human Rights Observatory, as well as by the Autistic Minority International NGO[141]. Overall the ongoing underfunding of the system, the

[141] An overview, including all shadow reporting, the reporting for sessions and in regards to the List of issues is available online at http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?CountryCode=PRT&Lang=EN [last accessed 01/07/2017].

poor socio-political understanding of disability, as well as the low enforcement of measures in place, such as the introduction of workplace adaptations is criticised (Associação Portuguesa de Deficientes 2012; Autistic Minority International 2016; Loja, Costa, and Menezes 2011; Pinto and Pinto 2017; Pinto 2018).

Concluding remarks

Overall it can be claimed that the low employment rate, in particular for women with disabilities and the very low quotas in both the public and the private sector show that the present Portuguese employment support system is insufficient to facilitate the inclusion of persons with disabilities in the labour market. The measures in place offer on the one side only temporary support (e.g. traineeships) and on the other side they are inadequate to urge employers to employ disabled people on a long-term basis. As a consequence disabled people in Portugal remain economically dependent on their families and charity organisations, a fact that does not contribute to enhance the being seen as equal citizens by others. Assessing the experiences reported by the participant throughout the in-depth interviews, the following chapter further elaborates on the de-facto situation. It will be shown that while comprehensive and complex structures and policies exist in theory, the positive outcome for disabled people is still limited.

7 Monitoring individual experiences

In the previous two chapters the historical emergence of disability employment policies in Germany and Portugal has been outlined. It has further been shown how present policies have been shaped by the international disability rights framework. The aim of the present study is, however, not only to outline to what degree legislation at national level embodies the values and standards of the CRPD but also to investigate to what extent the measures in place affect the lives of people with disabilities in practice. The critical aim of the study is to analyse the practical application of the measures in place and to investigate in which way they produce a real positive change for disabled people. As outlined in the methodological part, to achieve this aim in-depth interviews have been conducted with persons with disabilities in Portugal and Germany (see Chapter 4). The following chapter summarises the results from these interviews. The critical analysis reveals that, in both countries, for people with disabilities interviewed for this study, exclusion from and discrimination in the labour market is still widespread. Whereas in Germany sheltered employment plays a significant role among the study participants, in particular in their subjective experiences of segregation, interviewees in Portugal tend to have a higher risk to be unemployed due to the limited availability of sufficient, comprehensive long-term support.

7.1 Individual experiences in Germany – disabled people between an exclusionary sheltered employment system and a discriminatory open labour market

As outlined in the methodological chapter, a purposeful sampling of 16 interviewees was recruited in Germany. The sample consisted of nine female and seven male study participants aged between 22 and 63 years old. In regard to the occupation status, the majority of participants (nine persons) were working in sheltered employment; the remaining seven participants had a paid occupation in the open labour market at the time of the interview. Comparing the occupation status with the type of disability, the sample suggests a relationships between the type of disability and the occupation status: All participants who had an intellectual or psycho-social disability were in sheltered employment, whereas five out of the six participants

with a physical disability and all participants with a sensory disability had a paid occupation in the open labour market. The present sample further indicates that not only the type of disability interferes with the type of employment but also the academic qualification. Only one study participant with a special education degree was working in the open labour market. Five of the six participants with a special education degree worked in sheltered employment. These numbers indicate that for many people attending special schools (in particular people with intellectual disabilities) the only possibility to participate in working life seems to be sheltered employment. This one way route has been subject to widespread criticism internationally (United Nations 2012b) as well as nationally (Detmar et al. 2008; BAG WfbM 2014; Schulz and Bungart 2014, 2016; Seeger 2011). Looking at the violations to human rights principles that this practice involve, the need to critically assess the work in sheltered workshop becomes obvious.

In regard to the human rights principles, 16 participants reported one or more situations related to work and employment in which they had a positive experience. Nonetheless, 14 participants reported at least one situation in which they felt that these human rights principles had been violated. In other words, only two participants did not report a situation in which they experienced a violation of at least one human rights principle. Although both female, these two participants differ considering the other socio-demographic characteristics: One of them had a hearing impairment and worked in the open labour market[142] and the other one had an intellectual impairment and worked in a sheltered employment[143]. None of the interviewees reported violations in regard to all five principles; however three participants[144] reported that four out of the five human rights principles considered in this study had been violated. Six participants[145] reported that three human rights principles had been violated.

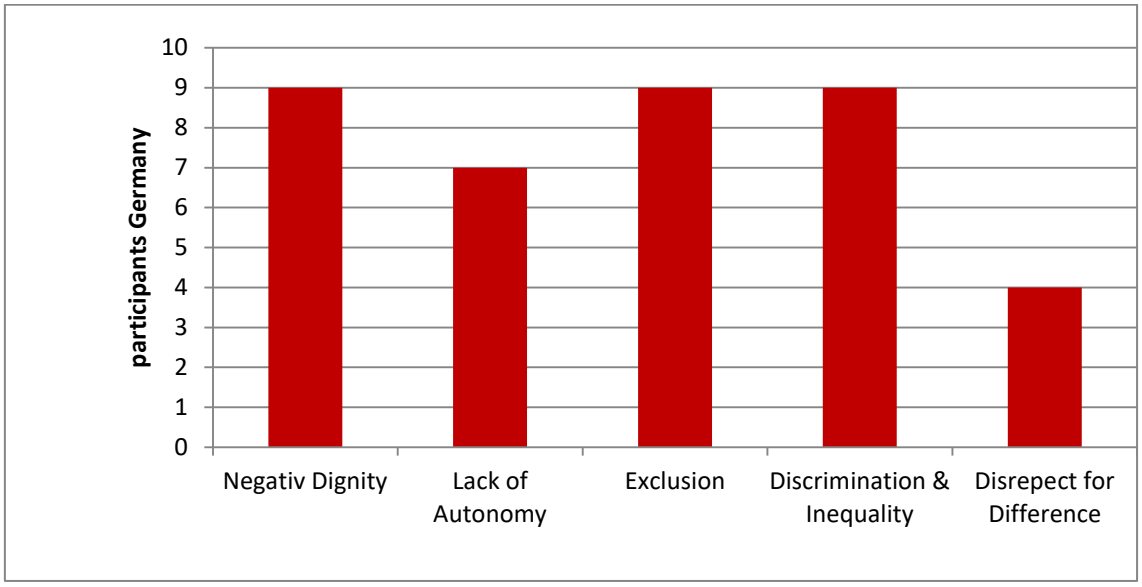
[142] EU.GE.BW.A.01

[143] EU.GE.BW.EF.16

[144] EU.GE.BW.A.03, EU.GE.BW.A.08, EU.GE.BW.EF.20

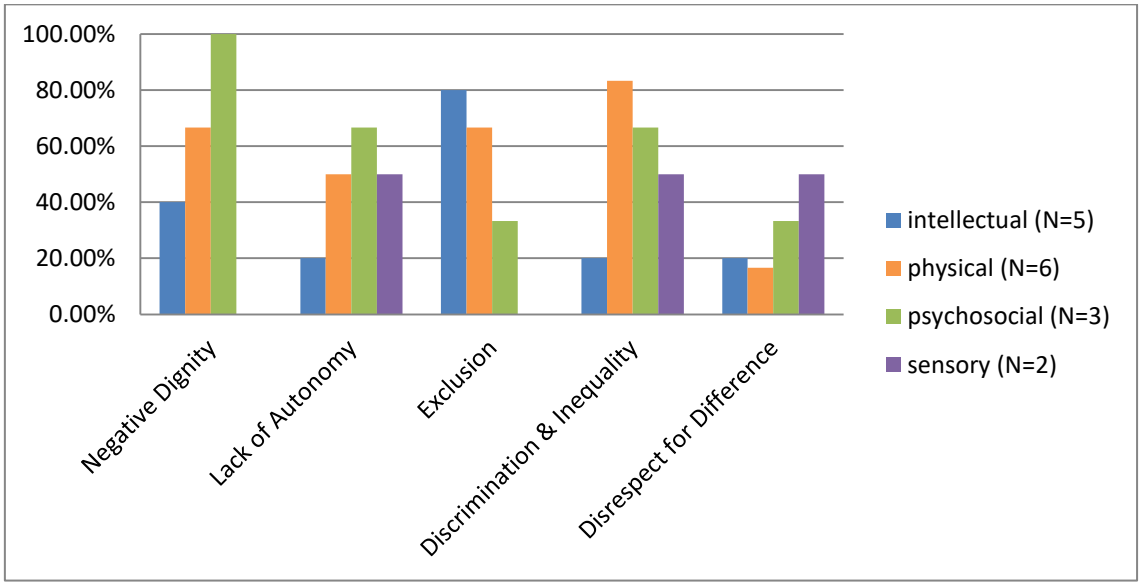
[145] EU.GE.BAY.A.06, EU.GE.BW.A.02, EU.GE.BW.A.04, EU.GE.BW.A.05, EU.GE.BW.A.07, EU.GE.BW.EF.14

Graph 27: Human Rights Violations experienced by the German participants



Depending on the type of disability, the human rights issues faced differed to a great extent; while interviewees with intellectual disabilities reported a high prevalence of exclusion (4 out of the 5 interviewees), interviewees with physical impairments reported the highest prevalence of feeling discriminated against (5 out of 6 interviewees) whereas the feeling that their dignity had been violated was highest amongst interviewees with a psycho-social disability (see graph 28).

Graph 28: Relative distribution of Human Rights violations reported, by type of disability in the German sample



7.1.1 Sheltered workshops - the source of exclusionary and undignified work experiences?!

If we examine the source of income in conjunction with the occupation status, one finding is outstanding: All participants working in sheltered workshops depend on additional sources of income, mostly in the form of welfare or pension payments (see Chapter 4), while six out of the seven participants who work in the open labour market have a sustainable income. These results indicate that the work in sheltered workshops does not comply with the concept of decent work (O´Reilly 2007) nor with article 27 of the CRPD which outlines that the right to work includes *the right to the opportunity to gain a living by work*. Moreover, the fact that all interviewees with a psycho-social disability experienced a situation in the context of sheltered employment in which they felt that their dignity had been violated sustains the argument that sheltered employment means undignified working conditions. The experiences of feeling *disrespected* and *devalued* were, on one side, connected to the type of organisation existing within sheltered workshops: disabled co-workers (disabled people who are admitted to sheltered workshops due to their incapacity to work in the open labour market) and people who work in the sheltered workshops as regular employees (such as supervisors, social workers etc.) have a different employee status in sheltered workshops in Germany (see chapter 5). The feeling that comes along with such a differentiation is described by one female participant as followed:

> "… I feel a bit as a second class human being… [pause] it´s not just me having such a feeling, many [co-workers] feel the same" (female, 58 years, psycho-social disability, sheltered workshop) [146]

This interviewee outlined that the feeling of being of less worth is linked to the fact that, whereas non-disabled employees, such as supervisors and social workers, have an extra room where they can make coffee or tea during breaks, disabled workers have no such facilities and they are not allowed to use the same room as their supervisors. Hurt feelings, low self-esteem, lack of confidence and sadness are also

[146] EU.GE.BW.A.02, 2015

caused by the type of work in a sheltered employment, as another interviewee with a psycho-social disability described:

> "It is extremely difficult for me to sit the whole day during work and to perform always the same monotone tasks. I am not getting motivated and I do not have the feeling that I am needed. You just do your tasks and this is extremely boring…" (male, 48 years, psycho-social disability, sheltered workshop) [147]

This interviewee defined his work as monotone and boring since he has to do always the same tasks. Furthermore, he has no control about the work tasks he does. Hence the work is not giving him a sense of purposefulness and he is not challenged by the work he is doing. The fact that monotone work often causes undignified working conditions has already been outlined in the context of industrial labour processes (Brock 1969; Pietsch 1952). Nonetheless, one interviewee with a psycho-social disability described the routine and the monotone work in the sheltered workshop as respectful to her needs and as positive to her personal well-being, as the monotone work is giving her some sense of security (EU.GE.BW.A.02 2015). The majority of interviewees working in a sheltered workshop (six out of nine) felt, however, in one or more situations, disrespected and devalued in the context of sheltered work.

Furthermore the feeling of exclusion was most predominant among study participants with an intellectual disability (see graph above). Four out of the five participants with an intellectual disability reported situations in which they felt excluded. These experiences were in two cases directly linked to the segregated nature of sheltered workshops: in one case, the bus that takes the participant to the sheltered workshops is not a regular public bus, but a special bus only used by workers from the sheltered workshop which further stigmatizes the participant as different and reinforced the feeling that he was excluded from the wider society (EU.GE.BW.A.04 2015). As Reeve claims, such types of support create additional psycho-emotional barriers which maintain social exclusion and isolation (Reeve 2013, 104). The direct admission from special schools to the sheltered workshops was also described as a structural barrier that prevented inclusion into mainstream support measures and the

[147] (EU.GE.BW.A.03 2015)

open labour market (EU.GE.BW.A.05 2015). Two interviewees reported that they were denied access to work in the open labour market due to their intellectual disability (EU.GE.BW.EF.15 2016, EU.GE.BW.EF.24 2016).

7.1.2 The open labour market in Germany – exclusionary to people with intellectual and psycho-social disabilities and discriminatory against people with physical disabilities

As outlined in Chapter 4, none of the study participants with an intellectual or psycho-social disability was working in the open labour market at the time of the interview. In addition, two out of the three persons with a psycho-social disability disclosed that the admission to a sheltered workshop was not a voluntary decision but one that was forced by the lack of alternatives [148] and connected support mechanisms[149]. The following situation clearly reflects such a lack of autonomy:

> "If I would have refused to go to a sheltered workshop, my legal guardian wouldn´t have organised to get me out of the care facility" (female, 58 years, psycho-social disability, sheltered workshop)[150].

Similarly, one participant with an intellectual disability described that she was prevented from making her own decision because she lacked the relevant information about possible options. Her experience was related to the automatic transition from the special school to the closest sheltered workshop (EU.GE.BW.A.05 2015). At the time when she finished her special school education in 2010, she wanted to work in the open labour market as a storekeeper or a similar position. However, she thought she had no possibility to work in the open labour market. She was not provided with relevant information about existing support measures – instead, she was admitted to the closest sheltered workshop as all her other classmates.

In contrast to the experiences described above, the other four participants with intellectual disabilities described that their decisions were respected in the admission

[148] EU.GE.BW.A.03

[149] EU.GE.BW.A.02

[150] EU.GE.BW.A.02

process to the sheltered workshops. These interviewees described that they were able to decide about the kind of work they would be doing, as the following report exemplifies:

> "I have done an internship in a hospital in W. and there I had to serve people and I had to clean the whole day; I had to do early and night shifts, and late shifts. The schedule always changed. I have done this for three quarters of the year and then I became sick, I wanted to go back to my old work [sheltered employment] and they have kept my job unoccupied so I was able to return" (58 years, female, intellectual disability, sheltered workshop)[151].

In the majority of the cases, experiences of *distinctions, exclusions or restriction*s occurred in the open labour market. That the open labour market in Germany is neither accommodating the needs of disabled people nor welcoming people with disabilities becomes obvious in the shared experiences of the interviewees who work in the open labour market. Violations of the principle of non-discrimination were most prevalent among people with physical impairments (5 out of 6 interviewees) and were most often related to work in the open labour market. Two interviewees, who were both wheelchair users since birth, revealed that the discrimination took place during the application process in the open labour market:

> "I even received a rejection letter with a note saying that there are special institutions for people with severe disabilities. The addresses of these institutions were enclosed" (female, 35 years, physical disability, open labour market)[152].

And another one disclosed:

> „I was invited to a pre-interview and I didn't feel comfortable. Many people were participating at this pre-interview and they wanted to know a lot about my disability. Even the company doctor was involved, he studied my medical reports. There was a lot of uncertainty amongst the decision makers. They were not sure if

[151] EU.GE.BW.EF.16

[152] EU.GE.BW.A.08

things would work out. They told me that the building was inaccessible and they offered me another position instead. However, the condition was that I had to do an internship of two weeks. The internship was meant to show if I could do the work or not..." (male, 22 years, physical impairment, open labour market) .[153]

The fact that their disability is visible played a role in the experiences of all these participants. In Germany, discrimination on the basis of disability is prohibited under the Constitution and under the Act of Equalisation of Persons with Disabilities (BGG). However, the BGG does not apply to private enterprises (see Chapter 5). Under § 81 SGB IX, public employers have a legal obligation to invite an applicant to a job interview if the applicant discloses that s/he has a severe disability. Nevertheless, there is no such obligation for private enterprises. The reported situations violate § 81 SGB IX, which states that employers are not allowed to discriminate against disabled employees (or applicants) due to their disability. Nevertheless, only one interviewee made a legal claim against the discriminatory employer (see first quote above). At the end she won the case and the company was forced to offer her the position. However, she declined the job offer, as she no longer felt comfortable working with people who discriminated against her at first.

The same interviewee also reported that the quota system played a positive role in helping her to get a contract with another company:

"One reason [to employ me] was probably the fact that the company wants or has to fulfil its obligation under the quota law […] I think the quota enforces the employment of disabled people in the open labour market. Without the quota this wouldn't be the case… I am convinced that if there were not a quota system, less disabled people would be employed" (female, 35 years, physical disability, open labour market)[154].

Another interviewee who also functions as a disability ombudsman in the company she works for, disclosed:

[153] EU.GE.BW.A.10

[154] EU.GE.BW.A.08

> "In every interview or even prior to the interview, the applications are gone through to find applications of persons with a severe disability. These applications are definitely promoted" (female, 60 years, physical disability, open labour market)[155].

The quota law in Germany applies to both, public and private employers. However, it is only applicable to companies who employ at least 20 people. While the quota might support that people with disabilities are promoted in the application process, the quota cannot prevent discriminatory attitudes to be widespread. One interviewee with a physical impairment experienced such a discriminatory attitude during an internship she was doing in the open labour market:

> „Everyone is friendly, but there is a psychological barrier … They [colleagues in the shop where she is doing an internship] do not dare to ask me something." (female, 37 years, physical disability, sheltered workshop)[156].

The psychological barrier, often caused by the common 'fear of disability' (Ellis 2008, 7), is also described by another interviewee as the source of discriminatory attitudes:

> "Everyone says, he is having MS [Multiple Sclerosis] and many are afraid of this, cause they don't know anything about this kind of illness … " (male, 36 years, physical disability, open labour market)[157].

In contrast, the low prevalence of reported discriminatory attitudes amongst people with an intellectual disability (only one out of five interviewees) is closely connected to their employment in a sheltered workshop[158]. Sheltered workshops are by law obliged to offer people with disability, who are unable to work in the open labour market, the right to work, for as long as they are able to produce 'a minimum

[155] EU.GE.BW.EF.20

[156] EU.GE.BAY.A.06

[157] EU.GE.BW.A.07

[158]The prevalence of discrimination and inequality is higher amongst people working in the open labour market (71,43%) than amongst interviewees working in sheltered workshops (44 %).

amount of economically useful work' (SGB IX § 136, para. 2). By legislation, the job in the sheltered workshop needs to be adjusted to disabled people's needs and abilities. However, and in contrast to such 'alternative' employment, the reports collected from participants show that the open labour market is often not considerate of disabled people's needs. Inflexible work arrangements and inadequate support systems as well as inaccessible environments, such as inaccessible public transportation [159] and inaccessible emergency and fire doors[160] are serving as restrictions that hinder the full participation of people with disabilities. One wheelchair-user disclosed:

> „There are barriers, for example the doors are difficult to open. But there is nothing you can do, because they are fire doors and they have to close automatically due to regulations… or another example are the coffee tables, which are high tables, too high for wheelchair users…" (female, 35 years, physical disability, open labour market) [161].

Another wheelchair user experienced similar barriers:

> "During my practical placements I am working in different departments. It is not making sense to rebuild the environment and make it accessible as I am working there only for a few weeks. There are often doors I can't pass by myself because I cannot open them. They are fire doors" (male, 22 years, physical impairment, open labour market) [162].

These examples show that the existing legislation is not sufficient, as the Act of Equalisation of Persons with Disabilities (Behinderungsgleichstellungsgesetz (BGG) that came into force in 2002, only applies to the public sector; private enterprises are not covered under the act and hence have no obligation to be accessible unless a disabled

[159] EU.GE.BW.EF.21

[160] EU.GE.BW.A.08, EU.GE.BW.A.10

[161] EU.GE.BW.A.08

[162] EU.GE.BW.A.10

person who requires accommodation is employed. Consequently, barriers and inaccessibility continue to exist in many workplaces.

One interviewee disclosed that due to the progressive development of his Multiple Sclerosis he slowly became severely disabled while he was already working in the open labour market. At first he experienced exclusionary attitudes; the employer tried to convince him to retire due to his disability and he only felt that he was included in his company after being resistant and becoming an ombudsman for disabled employees in the company[163]. A similar experience was reported by another interviewee who became paralysed due to a work-related accident. Since the accident he became a wheelchair user and while he first experienced many bureaucratic barriers and discriminatory attitudes, everyone slowly became aware of the benefits that an accessible work environment offers to everyone[164]. Although he still experiences barriers if he wants to come to work by public transportation - the railway lines are too low and he cannot enter the trains without the help of others - he has experienced no physical barriers in his workplace. The building in which he is working is accessible to wheelchair users; there are lifts and toilets for disabled people that provide a barrier-free environment and that enabled him to return to his former workplace after the accident:

> "The building was built in 1991, as far as I know. Back then they discussed disability issues and they built a toilet for disabled people. They probably asked themselves if it was really necessary and if they'd really need a disabled toilet as no disabled person was working there at the time. In the meantime, we are at least two wheelchair users working here. And these are only the people I know of. In the meantime they realised what they needed it for. The infrastructure is perfect; we have everything from lifts to disabled toilets" (male, 54 years, physical impaired, open labour market)[165].

[163] EU.GE.BW.A.07

[164] EU.GE.BW.EF.21

[165] EU.GE.BW.EF.21

These shared experiences show that the line between feeling included or feeling excluded is a thin one and that despite comprehensive measures in place, barriers and restrictions are still widespread.

In regards to the ways in which, those affected by discrimination, dealt with those situations, and although nine interviewees experienced discriminatory attitudes and inequality in the area of work and employment, only two participants were resistant and only one made a legal complaint, when discrimination occurred. The most common response (5 interviewees) to a situation in which a human rights principle was violated was to *distance oneself from the situation*:

> "Sometimes I feel embarrassed. For example, when we have team meetings, many colleagues are talking at once. They know what they are talking about. But I am just sitting there and don't say anything, because I don't feel confident to participate in the conversation" (female, 20 years, hearing impaired, open labour market)[166].

Another one described her changing behaviour since she became disabled due to back injuries:

> "I withdraw myself; I withdraw myself from many people. This is something I have not been doing in the past. In the past I used to integrate myself … But then I blocked everything and I said, I do not have to do this, I do not want this…" (female, 60 years, physical disability, open labour market)[167].

To *distance* oneself from hurting situations, as a response to abuse and discrimination is occurring across all age groups and all types of disabilities. An outstanding attribute is that all five interviewees who told that they reacted in such a way were female. *Fear*, *lack of access* and *the feeling that nothing would have happened* were mentioned each once by a participant as a reason why an occurred discrimination was not reported. For instance, a young participant feared that if she

[166] EU.GE.BW.EF.14

[167] EU.GE.BW.EF.20

had put through her claim and get her rights granted, she might have experienced further difficulties:

> "I didn´t want to put the claim through, because the women [who was discriminating against her] would have made my life even harder" (female, 35 years, physical disability, open labour market)[168].

Lack of access to information or support, which would have supported a legal claim, prevented another participant from further action:

> "To find the person in charge is extremely difficult. Basically you get lost" (male, 48 years, psycho-social disability, sheltered workshop) [169].

Economic (n=3) and legislative (n=2) matters were perceived as the main causes of discrimination. For example, the low income in sheltered workshops was mentioned by two interviewees as the cause of the discrimination:

> "You have to survive from month to month. Sometimes I think this is really depressing and there is no hope that this circumstance might change in the future" (female, 58 years old, psycho-social disability, sheltered workshop)[170].

However, economic difficulties/barriers also occur in the open labour market when someone acquires a disability while working. The interplay between the different payment schemes of sick benefits[171], disability benefits and insurance compensation payments that aim to protect someone who becomes disabled due to a work related accident often results in further obstacles, as one participant disclosed:

> "They [employer] demanded that I pay my wage back within 14 days. But I hadn't received disability benefits yet, because the calculation of the disability payment hadn't been done yet. … Back then I thought how can you be required to pay it

[168] EU.GE.BW.A.08 2015

[169] EU.GE.BW.A.03

[170] EU.GE.BW.A.02

[171] In Germany the employer has to cover sick payments for up to six weeks. After six weeks the health insurance pays a reduced amount of the sick benefits.

back, if you haven't received the disability benefits? In such a situation you really have a financial problem and you know the disability benefits are going to be substantially lower. But the company did not care about these circumstances. They left me alone with this …" (male, 36 years, physical disability, open labour market)[172].

The complex legal and bureaucratic way to have a severe disability certified is also described as a legal cause of discrimination. One interviewee, who went through the process to have his disability status assessed and who was at the time of the interview functioning as an ombudsman for disabled people disclosed that the degree of disability is often estimated very low by the assessing authorities. People have to take further legal action to have their disability status properly acknowledged. To lodge an appeal is a time consuming process which can take up to 2-3 years and demands a lot of strength and will power[173].

In contrast to Germany, in Portugal 10 out of the 21 study participants disclosed that they chose resistance to confront discriminatory attitudes in the open labour market. The following section further outlines the subjective experiences collected in Portugal, a country that in contrast to Germany has a less comprehensive system of sheltered employment for disabled people.

7.2 Individual experiences in Portugal – disabled people on the edge of society - caught between insufficient short term support and unemployment

"I am a fighter. I do not give up. I am very independent. I am fighting, but at this point in life, it is not easy" (female, 57 years, sensory (visual) disability, not working)[174].

In Portugal – as in Germany - individual experiences were gathered through in-depth interviews. In total 22 interviews provided the *de facto* information for Portugal.

[172] EU.GE.BW.A.07

[173] EU.GE.BW.A.07

[174] EU.PT.LX.EF.05

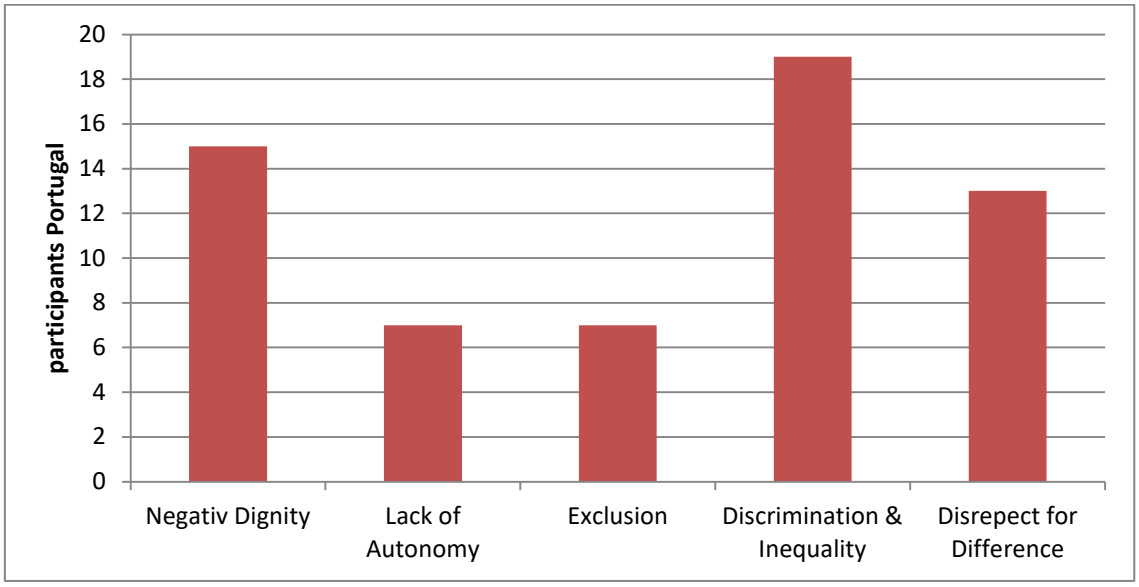
While in Germany all participants were either in paid employment in the open labour market or were working in sheltered workshops, half of the participants (n=11) in Portugal were not working at all. As in Germany, differences become obvious when assessing the occupation status in conjunction with the type of disability. In the Portuguese sample, the majority of people with physical impairments (six out of seven) were working in paid employment. Only one interviewee with a physical impairment was unemployed. In contrast, all four interviewees with an intellectual disability were not working and none of the interviewees with a psycho-social disability was in paid employment at the time of the interview. The majority of people with a sensory disability (four out of seven) were not working (see chapter 4). Furthermore, in Portugal, all participants who reported that they are employed in the open labour market have some school education. The education level of the participants who were unemployed ranged from primary school education (4 interviewees) to University degrees (n=2) and one hold a high school degree (n= 1). Concerning the human rights principles in the life domain of work and employment, all participants reported either a positive experience (n=7) or a situation in which they felt that human rights principles had been violated (n=21). Only one male physically disabled participant[175] reported no situation related to a human rights abuse in the area of work and employment. At the time of the interview he was working in the open labour market. In contrast to Germany, two interviewees experienced human rights violations in regard to all five principles[176]; three interviewees reported that four out of the five human rights principles had been violated[177].

[175] EU.PT.LX.J.04

[176] EU.PT.LX.EF.05; EU.PT.VNG.C.01

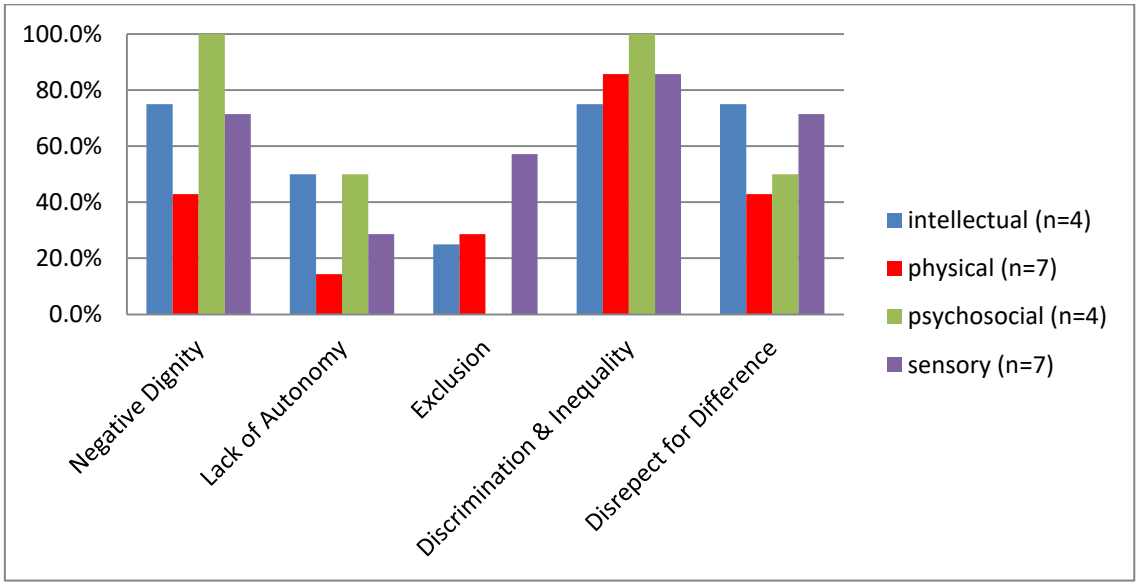
[177] EU.PT.ALG.F.02; EU.PT.LX.EF.01; EU.PT.VNG.C.01

Graph 29: Human Rights Violations experienced by the Portuguese participants



While feelings of exclusion and lack of autonomy have a higher relative prevalence among the German interviewees, experiences of indignity, discrimination and disrespect of differences were more often reported in Portugal. As in Germany, experiences differ when we distinguish between the variables considered relevant to the research. The graph below shows the differentiation when we distinguish between the different types of disability.

Graph 30: Relative distribution of experiences of human rights principles violations by type of disability in the Portuguese sample



Like in Germany, all interviewees with a psycho-social disability reported situations in which they felt that their dignity had been violated. Whereas in Germany, people with an intellectual disability reported a high level of exclusion but were less likely to experience violations of the other four principles, people with an intellectual disability in Portugal reported a low level of exclusion (only one out of four) but a higher prevalence of negative experiences in regard to the other principles. In contrast to Germany, where all participants with an intellectual disability were working in sheltered workshops, none of the participants with an intellectual disability in Portugal was working at the time of the interview.

7.2.1 The Portuguese labour market – discriminatory and exclusionary against people with disabilities

In Portugal, violations of the principle of non-discrimination and equality were most predominant. Nineteen out of the twenty-two interviewees reported a situation in which they felt discriminated against or treated unequally on the basis of their disability. The level of discrimination was high, both among participants who were working in the open labour market (6 out of 7) and people who were not working (10 out of 11). The subjective narratives show that discriminatory attitudes frequently occur during the application processes. The experience of one female participant, who tried to find a job after she graduated from university, is exemplary. When she mentioned her disability in the application, she did not receive any positive feedback from employers. As soon as she no longer mentioned her disability in the application letter, she received invitations for several job interviews (EU.PT.LX.EF.08 2015):

> "I sent my CV to get a job… at the beginning, when I finished my University I sent emails and said "Hi , I am …, I have an impairment and I made this and that". And nobody called me. And one day my father told me to change the text of my email. He told me that I should not mention my impairment. And I said okay, I will try. Within six months I was invited for eight interviews" (female, 32 years, physical disability, paid employment)[178].

[178] EU.PT.LX.EF.08

Another interviewee felt inferior in the application process, due to his CV which stated that he completed a professional training in an employment centre for disabled people:

> "When my curriculum stated that I completed a professional training at [name of the rehabilitation centre] I did not receive any feedback… then I spoke with other people and I wrote instead "IEFP" (the Portuguese employment agency]. From that moment, on I received several responses … this made me feel a bit… it made me feel sad and depressed" (male, 41 years, intellectual disability, not working)[179].

In another case, a visible impairment led to a discriminatory situation which was reported by a study participant with a physical disability:

> "I remember that I replied to a job announcement where they were looking for a worker to deliver cakes… a man called and asked if I had a driver license I said, yes, yes… I have and I told them how long I have been driving. But when I went there and they saw that I have only one hand, they first only stared at me and said "Sorry, I spoke to another applicant and he already took the job" (male, 58 years, physical disability, paid employment)[180].

As in Germany, anti-discrimination legislation is in place in Portugal. Article 5 of the Anti-discrimination legislation prohibits discrimination in the workplace, of both direct and indirect nature including in the hiring or termination process. Nevertheless, as in Germany, the burden of proof lies with the plaintiff. As outlined in chapter 6, for disabled applicants it is difficult to prove that the employers discriminated against them due to the disability. However, in Portugal, discriminatory attitudes are not only shown by employers, but also by the state employment agency, as one study participant disclosed:

> "I tried to find a job… I went to the employment agency to ask if they had any kind of work. They asked me 'Are you on a pension?' and I said "yes, yes, I am on a

[179] EU.PT.VNG.B.18

[180] EU.PT.LX.M.03

disability pension, but I have only been working for two years… I do not receive a good pension…" They told me, as I am already on a pension I am not a priority case for them and they sent me away…" (female, 44 years, psycho-social disability, not working)[181].

Furthermore, interviewees reported that discriminatory attitudes are even widespread in support measures such as professional internships that aim to promote inclusion in the labour market. Several participants disclosed that during their professional internships they had been treated differently than their non-disabled co-workers:

"I have a friend [without disability] who worked in the same programme than me. She was completing an internship too… but they paid her more. Because my internship was regulated under another stream, it was employment for people with disabilities and hers was not" (female, 32 years, physical disability, paid employment)[182].

Another one disclosed:

"People are not stupid; they knew I would stay, because it is difficult for me to find another job. I was there for free. They paid my colleges, but they did not pay me" (male, 31 years, physical disability, not working)[183].

Lack of accessibility both in the open labour market and to specifically designed support measures further increased the feeling of segregation and isolation. In particular for people with sensory disabilities (four out of seven participants) inadequate or lack of reasonable accommodation was a common experience in both vocational training measures and the open labour market:

"[In the vocational course] there is no sign language interpreter... The teacher told me "I am very sorry, but we do not have an interpreter." I was included in a course

[181] EU.PT.LX.EF.10

[182] EU.PT.LX.EF.08

[183] EU.PT.VNG.C.01

of hearing people. But after all how can I communicate and participate in such course without a sign language interpreter? ... So, I stayed at home and I took care of my sister, who was a baby at that time. Since I was 17, I have been looking after my sister; I have been staying at home without studying…. I stayed alone and spoke only little to others; I shut myself up in my own world… I ended up without work or studies for eight years; I stayed at home, always stayed at home…" (female, 26 years, sensory disability, student)[184].

Another interviewee reported similar experiences during her professional internship:

"In regard to support… There is none… I was doing an internship [in a hospital] for a year and the coordinator of my group never visited me…. Not once.... I prepared everything I needed for the internship by myself… I got no support…. I felt a bit excluded…" (female, 57 years, sensory disability, not working)[185].

However, not only the lack of adequate support measures in employment led to segregation and isolation, for people with sensory and physical disabilities in particular, inaccessible environments and in particular public transport systems served as further barriers:

"Sometimes in the metro and in the trains there are no safety lines… For example the train station 'Oriente' was built in 1998. By that time, the accessibility law was already in place which outlines that public places need to be made accessible… but the station "Oriente" is not really accessible…" (male, 48 years, visually impaired, paid employment)[186].

Similar experiences are shared by another participant:

"For me it is impossible to get to work without a car. It is impossible to go by public transport in Lisbon – with buses and trains… there are many architectural barriers

[184] EU.PT.LX.Q.11

[185] EU.PT.LX.EF.05

[186] EU.PT.LX.EF.09

and accessible buses only exist in theory. There are not enough accessible buses, this is a problem" (female, 57 years, sensory disability, not working)[187].

Another participant[188], a wheelchair user, reported that he could not enter the public building of the work authority to make a claim under the anti-discrimination legislation as the building was not accessible to wheelchair users. The staff had to come out and talk to him on the street. This experience shows that accessibility is a perquisite for an inclusive society. To have to submit a claim on the street not only violates confidentiality issues but also marks the person who is not able to access the building as different. It also shows that the present Accessibility law (Decree-law 163/2006, of August 8) has, at least in the reported case, no substantive effectiveness in practice.

7.2.2 Shortages of the Portuguese welfare state: When employment support only offers insufficient short term or employment access measures

Significant in the Portuguese context is the shortage of long term support measures. The widespread negative experiences reported by interviewees who have completed professional internship especially designed for disabled people show that measures who only focus on employment access are insufficient. A young female participant, who completed a training course in cleaning services, shared that the hotel she completed an internship on only used her manpower during high season without offering her a long-term employment prospect afterwards:

"They promised me a long-term contract at the beginning of the internship but I never received one… I was very annoyed and angry" (female, 29 years, intellectual disability, not working)[189].

Another participant disclosed:

[187] EU.PT.LX.EF.01

[188] EU.PT.VNG.C.01

[189] EU.PT.VNG.B.02

"When I was working I felt disrespected. I worked during the day and during nights and at the weekends without having a weekly rest… I had the feeling that I was used … that I was exploited … but I did not have a choice, the work was a compulsory part of the internship" (male, 41 years, psycho-social disability, not working).

Such experiences not only result in violations of their dignity but also violated the individual autonomy of the participants. Seven interviewees disclosed that they experienced a restriction to their autonomy. One deaf participant was restricted in her choice of the areas in which she could do an internship due to the lack of sign language interpreters. Although she would have loved to do an internship in the area of clothing or cooking, she had to do an internship/training in the area of metal and wood work[190]. Another participant outlined that she always received positive feedback during her internships as masseuse in a hospital; nevertheless, she was dismissed at the end of the traineeship period. Prior to her dismissal, she was given consecutive internship contracts for more than three years:

"If I had a choice, I would have stayed working in that hospital… however I was not given that opportunity when the maximum internship period ended" (female, 57 years, sensory disability, not working)[191].

An interviewee with an intellectual disability reported that she was badly treated and verbally insulted by her boss, but did not quit for more than one and a half years due to a lack of alternative choices:

"He [her boss] called me mad, he told me that I have mental problems….I did not have a choice, because I really needed that work. I put up with the situation one and a half years because I needed that work, but after that time I reached a point where I told myself 'the advantages do not compensate for my ill-health or my life'.

[190] EU.PT.LX.Q.11

[191] EU.PT.LX.EF.05

The offenses started to affect my mental status and therefore I gave up" (female, 41 years, intellectual disability, not working)[192].

The narratives show that even when people were in traineeships designed for disabled people they experienced powerlessness and felt inferior. The support in place was insufficient. Additionally, the current system of vocational training fails in several aspects; people participating in these programmes felt exploited and powerless and employers had no obligation to offer ongoing employment once internships came to an end. In Germany, for example, a protection period exists in which employers are obliged to employ disabled persons for a certain time period after supported internships otherwise the employer has to pay money back to the employment agency (see chapter 5).

The fact that unemployment and disability benefits in Portugal are very low (see chapter 6) contributes to the circumstance that the majority of interviewees depend on additional support. In comparison to the German sample, where the majority of additional support was provided by the state (50%), in Portugal the majority of support is provided by private and social networks (50%). Only one participant disclosed that he depended on welfare measures. The welfare society, and in particular the family thus plays a significant role among the interviewees. Ten study participants still live with their parents despite having reached adulthood. The pressure put on families and kinship relations can result in negative impacts as the experience of a study participant shows. The pressure to look for work and employment that is put on him by the employment centre and his family results in emotional harm:

"They tell me, you are a bad boy, you don't want to work, but you have to work …. They attack me with this kind of things. And I can see that this is not resolving anything. On the contrary… such pressure makes me feel a bit inferior compared to other people" (male, 35 years, intellectual disability, not working)[193].

[192] EU.PT.VNG.B.07

[193] EU.PT.VNG.B.08

Considering the living conditions and the lack of sufficient state support, it is no surprise that economic matters were named by seven participants as the main cause for discrimination. Participants disclosed that the recent economic crisis worsened their situation and even when in work, participants reported that their income was insufficient:

> "I earn the minimum wage[194]… and we have the small pension of my mother… it is really difficult" (female, 51 years, physical disability, paid employment)[195].

Until recently, disabled people lost their disability allowance once they started working. At the time of the interview, in 2015, one participant called for a revision of the current practice and bureaucratic procedure to obtain or reobtain the monthly disability allowance (social invalidity pension):

> "There is a problem… When you have a disability and you are at home, you receive an invalidity pension of about 200 € per month. But when you start working they cut this pension - because you work you are considered as not needy. But we think this is a big mistake, because you need to go somehow to your work, so you spent money to adapt the car or you need to pay someone to help to bring you to your job … and what happens when the job finishes? When the job finishes, we wait for five to six months until we start receiving the subsidy again... Imagine, I receive 200 €. Now I have the opportunity to work for three months, okay, I receive 300 or 400 €. Now, when I finish I will have to wait for 6 months without any kind of money. No one takes this risk" (male, 45 years, physical disability, paid employment)[196].

Considering that many people in Portugal only earn the minimum wage, this allowance is an important source of income. In part this problem has been addressed by the newly introduced Social Benefit to Inclusion (since 1st October 2017): People with a degree of disability of 80 % or more are entitled to the Social Benefit to

[194] In January 2018, the minimum salary in Portugal was 676,67 €/month.

[195] EU.PT.LX.EF.01

[196] EU.PT.LX.EF.04

Inclusion[197] regardless of other means of income. People with a degree of disability between 60 % and 80 % are entitled to up to 269,08 € (in 2018) depending on their degree of disability and their other incomes.

When it comes to the forms of response to abuse and discrimination most reported by participants, we found that, as in Germany, distancing was also a widespread response to discrimination and abuse. Six interviewees disclosed that they choose to distance themselves from the situation in which the violation occurred. As in Germany, this response to rights violations was more common amongst female participants (n=4) than amongst male participants (n=2). The results indicate that women are more likely to respond in a submissive to discrimination and abuse, as the following quote shows:

> "He [colleague] was making fun of me and he… he… he was looking to colleagues of mine…. I've been in the bank for almost two years … and after this situation I went to speak with my boss and told him, please sent me home, because I don't need this… so I stopped working at the bank" (female, 44 years, psycho-social disability, not working)[198].

In contrast to Germany more participants (10 out of the 21) disclosed that they chose resistance to confront discriminatory attitudes, least at the discursive level:

> "I am a fighter. I do not give up. I am very independent. I am fighting, but at this point in life, it is not easy… in my professional life… ah … I always fought for independence… I always loved my independence… " (female, 57 years, sensory (visual) disability, not working)[199].

Despite being resistant, only one interviewee[200] sought legal action, and reported the discriminatory attitudes and violations of her boss. She was successful with her

[197] In 2017: 264,32 € a month

[198] EU.PT.LX.EF.10

[199] EU.PT.LX.EF.05

[200] EU.PT.LX.EF.05

claim and received compensation. However she did not return to her former workplace. Lack of access is the most common reason for interviewees (n=6) not to report a situation of abuse or discrimination. In particular, lack of information and the inaccessibility of responsible authorities served as barriers:

> "To whom should I report? And whom could I ask about it? It is not going to be my boss whom I am going to ask… I can do nothing about this" (female, 26 years, sensory disability, student)[201].

> "I wanted to proceed with a legal claim… but I did not know how I could proceed. Maybe today I regret it a bit. If I would have made a legal claim, I might feel a bit better now. But I did not have the psychological conditions to proceed with a legal action. His words [former boss] against mine … but maybe I regret it now a bit…" (female, 41 years, intellectual disability, not working)[202].

Fear[203], lack of financial means[204], as well as self-blame[205] and the impression that nothing would have happened[206] were further reasons why violations were not reported:

> "I informed myself … and I decided not to report anything because the results could have been worse. Because, in reality, I have legally no right to anything. Thus they told me, it will depend on the good will of the judge. It was a risk and I did not take the risk" (male, 31 years, physical disability, not working)[207].

In short, the analysis of the subjective experiences shows that experiences differ in the two countries. Nevertheless, in both countries, obstacles and barriers are still

[201] EU.PT.LX.Q.11

[202] EU.PT.VNG.B.07

[203] EU.PT.ALG.F.02, EU.PT.VNG.B.15, EU.PT.VNG.C.01

[204] EU.PT.VNG.B.07

[205] EU.PT.LX.EF.10

[206] EU.PT.VNG.B.02, EU.PT.VNG.B.07

[207] EU.PT.VNG.C.01

persistent despite a range of measures and legislations in place. While in the German case, sheltered employment on the one side increases the risk of feeling excluded and in many aspects seems not to comply with standards of dignified work conditions; it provides an alternative employment option that does not exist at a similar scale in Portugal. In Portugal, family and kinship relations have to compensate for the shortage of long-term and insufficient support measures. The next chapter further explores the substantive effectiveness of the measures in place by drawing on a systematic comparative analysis.

8 Comparative analysis and policy recommendations

> "The future challenge for disability studies is to benefit from the new theoretical toolbox, without losing its audience among disabled people, the poorest of the poor in every society, and without losing its radical edge. Theory has to be conceived as a means to an end, rather than an end in itself. [...] the goal remains the same: to contribute to the emancipation of disabled people, whoever they are, and whatever they decide what emancipation means, and to the development of inclusive societies. This, in our view, continues to mean 'thinking globally' and 'acting locally' at the same time seeing and researching disabled lives as both constrained by social structures and as an active process of production which transforms social structures" (Corker and Shakespeare 2002, 15).

The aim of the present research was not only to analyse how the Convention on the Rights of Persons with Disabilities has been translated into national laws, policies and practices (Chapter 5 and 6), and how these measures impact the lived realities of persons with disabilities in Portugal and Germany (Chapter 7), but also to compare the two national approaches to *identify promising policy practices that can influence future policy development in both countries*. Building on the policy and law analysis and the experiences that the study participants shared throughout the interviews, the present chapter outlines the persisting barriers and obstacles to identify areas for future action and promising policy directions.

8.1 The late development of a socio-political understanding of disability

Analysing the historical roots of disability policies in both countries, it has been shown that in Germany as well as Portugal, a political understanding of disability has only emerged lately (Fontes 2014; Poore 2007; Eyre 2008). Whereas in Portugal the Fascist regime has prevented a political understanding of disability until its end in 1974 (Fontes 2014, 3), in Germany, Eugenic measures during World War II in particular, and the silence about disability issues after the war have prevented a politicisation of disability up until recently (Poore 2007; Eyre 2008). In both countries the international disability human rights framework and the Convention on the Rights of Persons with Disabilities has provided an empowering tool to review and challenge ableist policies

and structures (Lindqvist 2015). Nevertheless, despite the recent changes that have occurred in light of the international disability rights framework, the historical development still has an impact on present realities. The impact of historical events, former institutional and political arrangements and traditions on present realities has been referred to as 'path dependency' in the literature (Liebowitz and Margolis 2000).

In Portugal the weak welfare state provisions and the insufficient support measures (Santos 1991; Fontes 2009) contribute to the dependence of disabled people on their families and friends. The Portuguese case shows the absence of work environments that accommodate the needs and abilities of people who have been traditionally excluded from labour processes leads to unemployment and further dependence on family and friends. The lack of work opportunities for disabled people reinforces the medical/individual model of disability which marks disabled people as powerless, dependent, unfortunate, sick, useless, different and vulnerable (Hunt 1966; Sutherland 1981). Portugal has traditionally been classified among the Southern welfare states in which the family is the primary locus of solidarity and social support (Ferrera 1996; Karamessini 2007). As the analysis has shown the strong 'welfare society' (Santos 1991, 33–40) reduces the pressure on the government to introduce more comprehensive social policies for disabled people. At the same time the strong familialism (Karamessini 2007, 5), the impact of the recent financial crisis and the enduring austerity measures further restrict policy implementations which are truly embedded in a human rights agenda (Pinto 2018). In Germany, the widespread segregation of disabled people in both social and economic spheres hinders the full inclusion of disabled people in society (Eyre 2008; Poore 2007; Graumann 2009). Based on the study results the following paragraphs illustrate the persisting obstacles and barriers in more detail. It is further shown that not all disabled people are affected in the same way. The intersectionality of disability interferes with the outcomes of the policies and measures in place.

8.2 The lack of substantive effectiveness for all – the intersectional experience of disability

The present comparative analysis reveals that violations of the principles of autonomy and exclusion have a relatively higher prevalence amongst the German

participants than among the Portuguese participants. Considering the total numbers, study participants in Germany experienced more likely segregation and isolation (56.3% compared to 31.8%). To feel excluded or isolated was more often reported despite the fact that 44 % of the German study participants were in paid employment, compared to only 32% of the Portuguese sample. In both countries, anti-discrimination legislation has been implemented in recent years that prohibit discrimination on the grounds of disability and that inherits affirmative action and positive discrimination measures to promote the employment of disabled people in the open labour market. The anti-discrimination legislation in Germany is however broader than in Portugal. The German quota law, for example, applies to both, private and public employers and non-compliance results in a compensation levy employers have to pay annually. Based on the study results obtained at the individual level, it can be claimed that the German anti-discrimination protection is more substantive. The rate of reported discrimination and unequal treatment is lower in Germany (56.3 % of the study participants) compared to Portugal (86.4 % of the study participants). The following shows that Individual experiences vary when we take other human distinctions into consideration.

8.2.1 Being disabled and female – the disadvantaged position of female participants in both countries

In both countries, women with disabilities are further disadvantaged than their male counterparts, especially in regards to the principle of autonomy and self-determination – female study participants were more likely to report being unable or prevented from making decisions (Germany: 66,7%, Portugal 62,5%) on issues affecting work and employment than male participants (Germany and Portugal: 14,3%, Portugal). The new German disability legislation addresses gender bias by referring in several passages to disabled women and girls and their special social position. For instance, from 1st January 2018 on, it is obligatory to elect a female ombudsman in sheltered workshops who is responsible for all matters related to women working in sheltered workshops.

In Portugal, female participants were disadvantaged in four of the five principles in comparison with their male participants. Due to the strong concept of familialism that is still widespread in the Portuguese society (Karamessini 2007) female family

members often take the role of caretakers. Several female interviewees reported that they took care of family members such as parents, siblings and/or children due to limited and restricted choices in the labour market. In Portugal, the special needs of women with disabilities are not particularly mentioned in relevant legislation. In both countries distancing was a widespread response to discriminatory attitudes in particular among female participants. The results are an indication that women are more likely to show submissive behaviours in response to abuse and discrimination.

8.2.2 The impact of age – a divergent experience between Portugal and Germany

Whereas the disadvantaged position of female participants seems to be a transnational phenomenon, a binational differentiation occurs when we compare the experiences in regard to the three age clusters. In fact, while Portuguese study participants aged between 50 and 64 years experienced higher rates of violations than German participants of the same age group, Portuguese interviewees, aged between 18 and 35 years old had lower rates of human rights violations in three out of the five human rights principles than their German counterparts. In Germany, interviewees aged between 50 and 64 years were less likely to be affected by human rights violations than the German participants aged between 18 and 49 years. Only in regard to exclusion, German study participants aged between 36 and 49 years old had the lowest percentage. Younger German participants (aged between 18 and 35) felt most often a lack of self-determination and choice and reported higher incidences of segregation and isolation. Indeed, other German studies indicate that popular measures which target the inclusion of disabled people in the labour market such as the Occupational Integration Management (BEM or disability management) are used by companies and businesses to recruit disabled people among the existing workforce (Kardorff and Ohlbrecht 2013, 17). Jobseekers who enter the labour force from the outside are not supported by these measures to a similar degree as disabled people who are already employed or who obtained their disability while in employment. Exemplary are the experiences of the young German interviewees who disclosed several situations in the application process in which they felt discriminated on the basis of their disability (see chapter 7). It needs to be mentioned, however, that none

of the German participants was supported by the recently introduced measure of Supported Employment. As statistics show, the majority of persons using the measure of supported employment (61,7 % in 2015) are younger than 25 years old (Schulz and Bungart 2016). Supported Employment targets young adults graduating from special schools.

In contrast to Germany, most measures in Portugal focus on access to employment, e.g. through traineeships. This circumstance has an impact on the experiences of the participants if we distinguish between the three different age groups. Although participants in Portugal felt more often discriminated and/or treated unequally on the basis of disability across all three age groups, the difference between the German and the Portuguese samples is the highest among study participants aged between 50-64 years: All Portuguese participants aged between 50 and 64 years old reported a situation in which they experienced a *distinction, exclusion or restriction* on the basis of their disability, while only 50 % of the German sample of the same age had such an experience. The same applies to the principle of dignity. All Portuguese participants aged between 50 and 64 years experienced a situation in which they felt disrespected and devalued in their own experiences, and only one third of the German interviewees of the same age group reported such a situation.

Overall, people aged between 50 and 64 years old in Portugal reported higher violation rates in comparison with their younger counterparts. The binational comparison serves as an indication that the Portuguese measures support in particular access to work and the employability of young disabled people. The substantive lack of long-term and sustainable supports, already reported in the literature (Pinto 2018), is also sustained by this research. Additionally, disabled employees in Germany seem to have better protection mechanism in place than their Portuguese counterparts. As outlined in chapters 5 and 7, at least for people with disabilities that are employed, measures such as the Occupational Integration Management, the special dismissal protection and the ombudsman for disabled employees have a positive impact in Germany. Interviewees disclosed that they received support from ombudsmen for disabled people regarding disability-specific needs. In the majority of the cases, the ombudsman is a disabled person him/herself and can offer valuable peer support to

other disabled employees in reporting discriminatory behaviours and enforcing their rights. Frequently, ombudsmen assist disabled people in the complex bureaucratic processes to either have the disability officially acknowledged or to have disability-specific needs adequately addressed.

8.2.3 The type of disability - an important distinction when it comes to subjective experiences of exclusion and discrimination

Although age and gender play their part too, the type of impairment seems to influence the subjective experiences the most (see chapter 7). In both countries, people with an intellectual or a psycho-social disability were in a specific disadvantaged position. Whereas, in Germany all interviewees with an intellectual or psycho-social disability were working in sheltered employment, in Portugal, none of the study participants with these types of disabilities was in paid occupation. This group was, instead, completely excluded from work processes. Such findings are in line with research from other countries that show that people with psycho-social disabilities are amongst the most excluded in the labour market and that the type of disability is crucial for employability (Boman et al. 2015).

The high percentage of German participants who feel excluded or isolated and the strong connection of exclusion and sheltered workshops calls for action and a substantive alteration of the widespread segregation in the German labour market. It can be argued that the broad system of sheltered workshops suppresses collective action and diminishes the pressure on the open labour market to become more inclusive. The newly introduced Job Budget[208] aims to alter the present system: people who are entitled to work in a sheltered employment have the opportunity to receive a cash benefit that enables them to pay a wage subsidy to their employer that covers performance reductions (§ 61 SGB IX). At the present moment, outcomes about the use and the effectiveness of such a Job Budget are outstanding. The shared experience of the study participants, who have voluntarily admitted themselves to sheltered workshops due to negative experiences in the open labour market, shows that a more flexible transition between sheltered workshops and the open labour market is in

[208] The Job Budget came into force on 1st January 2018.

some cases necessary. The alteration of the present inflexible system[209] is a step in the right direction. On the other hand, the fact that all participants with an intellectual disability in Portugal were excluded from the labour market shows that long-term and substantive support is necessary to include people with intellectual disabilities in the mainstream world of work. As already shown in other research (e.g. Hall and Wilton 2011; Sainsbury 2017), the abolition of segregated workshops without adequate alternatives does not appear to be a promising solution.

Like their peers with an intellectual disability, all German participants with a psycho-social disability were working in sheltered workshops. People with psycho-social disabilities interviewed in Germany reported high rates of human rights violations. In both countries, people with a psycho-social disability make up the only group in which all study participants reported feeling devalued and disrespect in their own experiences or opinions and they also reported a high level of discrimination. Several issues affect in particular people with psycho-social disabilities; (1) the assessment and effects of psycho-social disability are often complex and invisible to the wider public, (2) many policies in place do not address the needs of people with a psycho-social disability adequately. For example, inclusion companies (former integration companies) in Germany were originally established to offer access to the open labour market to people with a psycho-social disability, in particular. However, the majority of people working today in integration projects are people with physical disabilities (Detmar et al. 2008, 9). The growing admission numbers of people with psycho-social disabilities to sheltered workshops in Germany further indicates that people with psycho-social disabilities belong to the group which is most disadvantaged in the present labour market and that the existing employment measures are insufficient to protect this group. The Portuguese experiences point in the same direction (see chapter 7).

Despite the fact that many measures in place support in particular people with a physical disability, study participants with a physical disability experienced high rates

[209] Up until recently transitions from sheltered employment to the open labour market inherited a risk to lose benefits gained in the sheltered workshops. Furthermore the return to a sheltered workshop in cases in which the transition was unsuccessful was complex and highly bureaucratic (see chapter 5).

of discrimination and inequality in Germany (83,3%) and Portugal (85,7%). In many cases, the visibility of their impairments played an important role. In both countries, interviewees with a physical disability reported that it was difficult to enter the labour market, as employers were reluctant to offer a job opportunity to someone who is obviously disabled. The existing anti-discrimination legislation in both countries, thus, proves ineffective at this regard. For example, in both countries the burden of proof remains with the plaintiff and there is no legal obligation in place that requires the employer to disclose the reasons for a rejection. The individual reports collected show that this circumstance serves as a further barrier. Lack of access and lack of financial means, as well as the feeling that nothing will happen hinders many disabled people to report a situation in which they are discriminated against. As a consequence, the number of participants who made a legal claim is very low[210].

In particular for persons with a physical disability, inaccessible environments serve as significant barrier. In both countries, inaccessible environments include an inaccessible public transportation system or inadequate adjustments that create psycho-emotional barriers that hinder participation in work and employment. The lack of access for a wheelchair user, even to the work authority building in Portugal, is a striking example that shows that even when legislation is in place, it lacks substantive effectiveness (Gubbels 2017). Although in both countries there is legislation in place that requires transport accessibility and accessibility in public buildings and spaces, there are no provisions that require accessibility in the private sector. Consequently private enterprises that offer the majority of jobs are only affected once a disabled person is employed. The reluctance interviewees experienced when trying to enter the labour market from the outside is an indication that employers fear the accessibility obligations that come along with employing a disabled person who needs accommodation.

Accessibility also plays a crucial role for people with a sensory disability. In Portugal, interviewees with a sensory disability reported that their disability-specific needs are not addressed adequately in the open labour market. A crucial problem

[210] In both countries, only one person took legal action and submitted a legal claim.

reported was the substantive lack of sign language interpreters and insufficient provision of technical devices in both the open labour market and employment measures which are specifically designed for disabled people. Although the law in both countries outlines that disability-specific needs have to be addressed and that accommodation measures and assistive devices need to be provided and are supported by the state, the bureaucratic procedures are in both countries complex and often prove ineffective in practice.

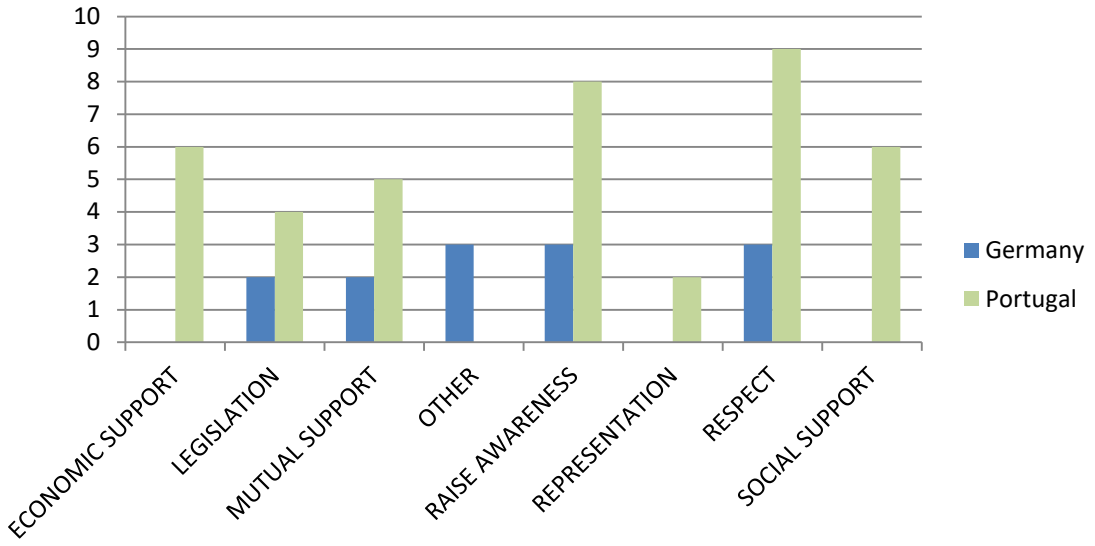
Overall, it has been shown that in Portugal measures are restricted to insufficient short term support that facilitates temporary work and precarious jobs and do not create meaningful and long term work opportunities, while in Germany the gap between insiders (disabled people who work in the open labour market) and outsiders (people who work in sheltered workshops) is vast. In both countries, women and people with intellectual and psycho-social disabilities are among the most disadvantaged.

Despite all persisting gaps and obstacles, the analysis also shows that there is scope for binational learning. Based on the systematic analysis and the recommendations the participants made throughout the interviews, future policy directions and promising disability employment policies are outlined in the following sections.

8.3 Which way to go? Future perspectives of disability employment policies. A binational learning experience

Traditionally disabled people have been widely excluded from policy and decision making processes (Barnes 1990; Sutherland 1981; Oliver 1990). The human rights approach tackles such oppressive structures and embraces emancipatory forms of knowledge production. In the present chapter the insight knowledge and wisdom of the study participants serve as valuable source for the future development of disability employment policies. The aim is to identify promising policy practices and directions that may serve as guidelines for future policy developments. The graph below shows the overall picture of the recommendations made by the interviewees.

Graph 31: Recommendations made by the Study participants in Portugal and Germany



8.3.1 Respect and peer support – the success story of the disabled ombudsmen in Germany

> "I am deaf, I have problems with communication. Other people have other problems; there are barriers for everyone, for every person…" (male, 29 years, sensory disability, internship)[211].

It was not the call for legislative or economic change that was made most often by the participants, but the request for more respect. In total, twelve interviewees (nine in Portugal and three in Germany) called for more respect. In their opinion, the government, employers and colleagues should be more considerate of the needs of disabled people, they should accept and respect human differences and treat people with disabilities as equal citizens. As outlined in Chapter one, Adorno argued that a truly emancipated society would be "the realization of universality in the reconciliation of differences"; such a society would be one in which "people can be different without fear" (Adorno 1951, 102) and in which "differences, distinctions, distances, and tensions—between people and between humankind and its environment—are regarded as normal and necessary, are defended and even celebrated" (Alway 1995, 69). The following quote highlights how a society that embraces human differences looks like in practice:

[211] EU.PT.LX.M.04

"I am lucky cause my office is opposite of the company's ombudsman for disabled employees. He always asks my opinion... In another building, they were planning to build a toilet for disabled people and I personally always felt offended by the fact that all disabled toilets are unisex toilets… now they build a female and a male disabled toilet …" (female, 35 years, physical disability, open labour market)[212].

The above quote highlights that people feel valued and accepted when their opinion is taking into consideration in decision making process. It further illustrates the important role the disability ombudsmen play in the German labour market. Having someone who supports you in your fight for equal enjoyment and access to rights serves as a source of mutual support, something seven interviewees in both countries called for. Disability ombudsmen also strengthen what Hall and Wilton have framed as the "collective action" of disabled people in the open labour market (Hall and Wilton 2011). In Germany, every business or company that employs more than five severely disabled people on a permanent basis has to facilitate the election of such ombudsmen. In Portugal there is no equivalent system in place; however, five Portuguese interviewees mentioned that it is important to share individual experiences and support each other with suggestions about how to deal with discrimination and abuse. Peer support is suggested as an important tool to empower people with disabilities to become aware and enforce their right to work and employment. As one of the Portuguese interviewees put it:

"I need someone I can ask a question about my situation... somebody who can clarify issues and explain my special situation to others" (female, 51 years, psycho-social disability, on sick leave)[213].

Closely linked to the issue of peer support and respect are awareness-raising measures. Several participants also stressed that awareness-raising is an important measure to increase the consciousness about disabled peoples' needs.

[212] EU.GE.BW.A.08

[213] EU.PT.ALG.F.02

8.3.2 Awareness raising – the need to confront social prejudices and common fears

In total, eleven interviewees, eight in Portugal and three in Germany, recommended that awareness-raising initiatives need to be strengthened. One German interviewee outlined that while public awareness has increased in recent years, existing awareness-raising campaigns are often merely symbolic. He made suggestions about how they could be improved:

> "In regard to politics a lot has changed. Public awareness has strongly increased and in our company disability awareness has increased a lot. Recently we had a "Diversity Day". It was well organised. They organised a wheelchair race in which there was a wheelchair user and a non-disabled person competing against each other. It was fun and a nice day, but it had no use in the long run. I suggested that we put someone in a wheelchair at the entrance of the company and then give him/her half an hour or 45 Minutes to have a lunch break... then able- bodied people could experience the reality of a wheelchair user. There are only two lowered curbs on the whole company ground which are accessible to wheelchair users. In the canteen you have the problem with the high counters. Sitting in a wheelchair you cannot see the meals and if you are sitting in a wheelchair you need your hands to move and you cannot hold a tablet..." (male, 36 years, physical disability, open labour market)[214].

Portuguese participants, in particular, stressed that awareness-raising measures need to go behind providing information to employers. Although it is an important step to raise awareness among potential employers and future colleagues, the general social attitudes towards disabled people need to change as the following quote shows:

> "Education, professional training and the whole employment measures need to confront the idea that disabled people cannot exercise professional and social roles

[214] EU.GE.BW.A.07

in the same manner as other citizens" (male, 48 years, visually impaired, paid employment)[215]

The narrative of a young participant who has very complex support needs exemplifiers the possibilities that exist, if a supportive work environment is provided. The experience also shows that raising awareness is a daily individual task that requires lots of personal strength and effort:

„At the beginning, when you start in a new department, it is strange for both sides. At the beginning the colleagues don't know how they can help me and how I will react to their support. The first few days in a new department, I have to ask for assistance when I need some. I try to act very openly so people feel comfortable to ask questions. When they feel confident to ask they don't talk about me behind my back. They feel free to ask questions and I get the feeling that I can rely on their support, if I need some … By doing so, I create an open atmosphere and they get the feeling they don't have to pay special attention to me. They know I am there and I call for help, if I need to … I am somebody who acts naturally and I deal with things as they are. If I need help, I ask for help … I think it is crucial to be open and not to be afraid. I think openness is the most important thing. You can't expect help from others without telling them your needs. You have to tell them what you need and then it usually works very well" (male, 22 years, physical disability, open labour market)[216].

The above report was made by a participant with very high and complex needs who is using an electric wheelchair. During 24 hours, he needs several measures of assistance, including somebody to help him with his urine bottle, when he goes to the toilet and someone to feed him, if he cannot cut the food by himself. His ability to assert the support he needs with self-confidence has its roots in his uprising as he explained:

[215] EU.PT.LX.EF.09

[216] EU.GE.BW.A.10

„My openness has developed throughout the years. … My parents always enabled me to do what I wanted to do. They had the attitude that if things go well, it's good and if I need help, they support me"(male, 22 years, physical disability, open labour market)[217].

The daily effort the interviewee makes contributes to the further education of society. Day by day he confronts social prejudices and the common fear of disability (Hunt 1966; Ellis 2008). He is a striking example that people with severe restrictions and very high support needs can equally participate in work and employment if a supportive, accessible and accommodating environment is provided.

Employer awards that honour employers and companies who serve as a good example are one way to confront social prejudices and to increase awareness. Such measures exist in Germany and Portugal and they are important to raise awareness and show best practice solutions. However, they have limited scope. Accessibility is a key factor. Although both countries have anti-discrimination legislation in place that tackles direct and indirect discrimination, the stories collected show that discrimination is still widespread and legal action is rather an exception. Only two interviewees, one in Germany and one in Portugal, made a legal claim under the existing anti-discrimination legislation. Furthermore, a supportive and accessible environment, that is considerate of disabled people's needs also requires some protection mechanisms to ensure that those who voice their needs are not subject to arbitrary behaviours.

8.3.3 Legislation which works in practice

The comparative analysis has revealed that protection measures in Germany are more comprehensive than in Portugal. For example, vocational traineeships for disabled people in Germany inherit a "protection period" which ensures that employers who get financial support during the training period have to ensure that the disabled person is employed for a subsequent period after the training period is finished. Furthermore disabled people in Germany have a special dismissal protection

[217] EU.GE.BW.A.10

when they are employed. Such measures combat at least to a certain degree short-term employment and the misuse of disabled people's labour force - an experience which various Portuguese participants faced.

In addition, several recommendations have been made by the Portuguese interviewees to extend the quota system to the private sector. Their claim can be supported by the binational comparison. Although there is still space for improvement (Kardorff and Ohlbrecht 2013; Rauch 2005; Fietz, Gebauer, and Hammer 2011) the German employment quota proofs to be more effective than the Portuguese system: (1) the employment quota does apply to both, the private and the public sector; (2) there is a compensation levy in place which means that employers who do not fulfil their obligation under the quota have to pay a compensation levy; and (3) all employers who are affected by the quota (employers with at least 20 employees) have to report their employment figures to an agency (Integration Offices) on an annual basis. The Integration Offices publish the data once a year. The Integration Offices further offers advice and support to employers and disabled employees. Although the legislation only applies to companies that employ at least 20 employees on a permanent basis, the existence of such a quota was described as supportive by German participants.

Although it has been argued that in Germany the existing legislation creates an "insider-outsider effect" (Kardorff and Ohlbrecht 2013, 17), which means disabled people who are already employed have better protection in place than disabled jobseekers or disabled people working in sheltered workshops, the Portuguese individual reports show that where such mechanisms (protection period, quota in the private sector, ombudsmen) do not exist, disabled people experience further discrimination and exclusion. To provide sustainable and long-term employment the State becomes necessary as a sanctioning, organizing and executive power (Habermas 1996, 134). In practice this means that policies and measures in place need to be closely monitored, and arbitrary behaviours of employers who misuse existing measures need to be sanctioned to enforce their practical effectiveness. The German quota legislation, with its independent and annual reporting mechanism, is a good example of how the State can fulfil its sanctioning power. The Integration Offices

collect data on an annual basis to execute power and sanction employers who do not comply with the quota. The analysis has shown that such a mechanism is more effective than the Portuguese quota law, which does not involve sanctions nor is properly enforced.

In addition to legislation that facilitates access to employment and strengthens and supports the employment of disabled people, economic support is needed to facilitate the transition from non-working lives to work and employment. This point is addressed in the next section.

8.3.4 Economic support that facilitates the transition to work and employment

Traditionally, disabled lives have been classified as non-working lives. Disability pensions are in many countries only granted if a person can proof his/her inability to work. As outlined above, such traditional welfare models need to change if an active citizenship is promoted. In Portugal, several recommendations referred to economic support and legislative change such as the improvement and update of training courses and the creation of service providers that are closely connected to business and the labour market and that offer on-the-job training. One participant noted:

> "Training courses are still offering the same training as 20 years ago, service providers have not adapted their training to the current labour market. Yesterday I talked with someone about this and she told me that they have a training course for baristas… and she said the way they are teaching it is the same as 10 years ago. But today it is completely different. Different skills are necessary to work in a café today. Nevertheless the curricula are not adapted to the new criteria. When people finish the course, they get a diploma, a certificate, but no one wants to hire them" (male, 45 years, physical impairment, in paid employment)[218].

Another important issue was the revision of current bureaucratic procedures to access the monthly disability allowance. As outlined in the literature, a more equitable and less stigmatising distribution system is required (Barnes 2003a) that recognises

[218] EU.PT.LX.EF.04

that disabled people might have ongoing medical and social support needs and welfare support should continue even when a person is in employment (Quinn and Degener 2002a, 18). Portuguese participants disclosed that the present practice and bureaucratic procedure to obtain or reobtain the monthly disability allowance (social invalidity pension) hinders people with disabilities to enter the labour market. One participant described that people with disabilities fear to be left in a worse economic situation due to the waiting time that occurs when people have to reobtain the monthly disability pension and/or due to expenses that might occur when people take up a job (see chapter 7.2). The issue has been addressed in recent legislative changes. Since 1st October 2017, in Portugal, people with a degree of disability above 80% are entitled to a monthly amount of 264,32 € regardless of other income[219] (see chapter 6). How the legislative change will affect the employment situation of disabled people is yet to be seen. Economic support has also been strengthened by previous legislative changes in Germany. While until the end of 2017, people who have been working in sheltered workshops risked to lose their incapacity pensions if they attempted to make a transition into the open labour market, people with disabilities have now (since 1st January 2018) a right to return to sheltered workshops if their transition to the open labour market is unsuccessfully. Furthermore a personal "Job Budget" ("Budget für Arbeit") was introduced which provides people who are entitled to work in a sheltered employment with a cash benefit that enables them to pay up to 75% of the gross income to an employer if the employer provides them with an employment in the open labour market. The new measures acknowledge that the present labour market is not accommodating all people with disabilities and that comprehensive long-term support is needed to enable employment in the labour market. Furthermore the new BTHG increases the threshold of disabled people who have an income and who require disability related support. Prior to 2018, the income and assets of partners who live in the same household were included when disability related support needs were assessed. This is no longer the case and, as a consequence, the responsibility on families to provide for a disabled person was further reduced. In short, in both countries first steps have been taken to better address disability related costs when

[219] For people with a degree of disability between 60% and 80% there is a limit to what they can earn while still receiving the benefit (see chapter 6)

people are in paid work and social barriers in the present world of work are better acknowledged. However, the narratives show that there is still a long way to go to create an inclusive world of work for people with disabilities in both Germany and Portugal. Future employment policies thus need to provide an alternative to both, the segregation of sheltered employment on the one hand, and the lack of accessible and suitable employment structures, on the other hand.

9 Conclusion

The aim of the present study has been to critically reflect on the extent to which the right to work and employment has been enshrined in national legislation, policies, programmes, and practices, and how it is being experienced by people with disabilities in the German and Portuguese context. The purpose of the comparative analysis was to identify best *practice policies that can influence future policy development in both countries*.

To complete such a comprehensive task this empirical study reviewed three major theoretical frameworks: namely, critical disability theory, the theory of human rights and the sociology of work. Critical disability theory offers a politicized view and re-evaluation of explanatory paradigms used to understand the lived experience of disabled people (Meekosha and Shuttleworth 2009; Devlin and Pothier 2006). The goal of critical disability theory is to challenge neoliberal norms and values so that disabled people can fully participate in contemporary societies and are recognized as part of the human diversity (Devlin and Pothier 2006; Rioux and Fraser 2006; Hosking 2008). Since the emergence of critical disability studies, disability scholars and activists have changed the way disability is dealt with in academic and political discourses (J. Campbell and Oliver 1996; Bickenbach 2012; Rioux 2002; Barnes 2003b). Claiming equal citizenship status, the human rights approach to disability challenges traditional paternalistic and oppressive structures (Rioux 2002). As a response to the newly emerged understanding of disability, many Western welfare states, including Portugal and Germany, have implemented legislation which embodies a human rights approach. At the international level, the adoption of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006 has been celebrated as an important step for people with disabilities to gain social justice and have their equal citizenship status recognised by the international community (Kayess and French 2008; Mégret 2008).

The literature review undertaken for this research showed that the human rights theory offers a holistic concept to analyse the situation of persons with disability and to outline the oppressive power relations, exclusionary and discriminatory structures and barriers that they face in everyday life. Acknowledging that disabled people need special provisions to meet equal opportunities, the Convention on the Rights of

Persons with Disabilities was deemed to serve as a blueprint for future policy developments. The Convention does not implement any new rights, however, it clarifies the obligations that States have to identify and adapt discriminatory and oppressive social structures that restrict persons with disabilities from fully enjoying all human rights and fundamental freedoms as defined in the International Bill of Human Rights. In addition, the monitoring obligation of the Convention was understood as a powerful tool for disabled people, their families and supporters, to analyse the *de facto* situation and ensure the substantive effectiveness of the Convention (Lindqvist 2004). The international human rights framework is, thus, viewed as playing an important role to hold States responsible and accountable for the citizenship status of persons with disabilities, while providing a standard against which to assess the current situation.

The literature further showed that among social policies which address disabled people's needs and promote their equal citizenship status, those related to inclusion in work and employment are central (Galer 2012; Abberley 2002). The concepts of work and employment have changed across time, place and culture. While at the beginning of the Western civilization work was the characteristic which excluded people from social status, work and employment have become central aspects of a valued social identity in contemporary societies (Beck 2001b; Abberley 2002). Determining who is entitled to citizenship status, workfare approaches have become predominant in social policy approaches including social policies that address disabled people. It has been shown that workfare measures often fall short in the context of disabled people, a group that belongs to the most marginalised in the labour market (Morris 2011; Soldatic and Chapman 2010; Owen and Harris 2012; Soldatic and Meekosha 2012). Critical disability scholars thus call for a radical transformation of the ontologies of work and employment (Abberley 2002; Soldatic and Chapman 2010; Becker 2015). The right to work and employment as enshrined in the disability human rights framework acknowledges the special position of disabled people in the labour market, and thus provides a suitable framework to critically monitor and assess the situation of disabled people in the labour market.

In turn, the empirical analysis revealed that, in both countries, Portugal and Germany, people with disabilities still experience widespread discrimination and exclusion in the area of work and employment, regardless of existing laws and policies that are increasingly framed within a human rights agenda. While in the German case sheltered employment, on the one hand, increases the risk of feeling excluded and in many aspects seems not to comply with standards of dignified work conditions, on the other hand, it provides an alternative employment option that does not exist at a similar scale in Portugal. In Portugal, family and kinship relations were found to have to compensate for the shortage of long-term employment and insufficient support measures (including in financial terms). The systematic comparative analysis further outlined that the intersectionality of disability interferes with the outcomes of the policies and measures in place. Whereas the disadvantaged position of female participants seems to be a transnational phenomenon, a binational differentiation occurs when the age of the participants is taken under consideration. In short, while the German system seems to provide a better protection mechanism for older disabled people who are in employment, the Portuguese measures mainly focus on access to work and employment and thus younger disabled jobseekers benefit from the social policies in place. In both countries, however, people with an intellectual or a psycho-social disability were found to be in a particularly disadvantaged position. Nevertheless, the initial attempt to alter the present system of sheltered employment in Germany seemed to lead in the right direction. International experiences have shown that in countries, such as in the United Kingdom where sheltered workshops have closed down, many people formerly employed in sheltered workshops, remain unemployed in the open labour market (Hall and Wilton 2011; Sainsbury 2017) when no alternative support measures are put in place.

Drawing from all the data collected and the comparative analysis undertaken in this research, the following policy recommendations can be drawn, to inform future disability policy development, particularly in the area of work and employment:

(1) Respect and peer support: The call for more respect and peer support was made most often by the participants. Participants reported that the system of ombudsman, that is obligatory for every employer in Germany that employ

more than five severely disabled people, strengthens peer support and increases the respect for disabled workers, and therefore it can be a promising practice for other countries to adopt.

(2) Awareness-raising: Closely linked to the issue of peer support and respect are awareness-raising measures. The collected data illustrated that public servants, such as people working in employment agencies, employers and colleagues are not aware of, and thus often do not accept and respect human differences and the specific needs of disabled people. Knowledge about disabled people's needs and abilities among the general public thus needs to increase. In addition, the study indicates that existing awareness-raising measures need to be further strengthened. Existing measures have been described as symbolic and ineffective. In general the dominant image that disabled people cannot participate in work processes needs to be transformed. As participants outlined these could be done by awareness-raising measures that include their personal day-to-day experiences.

(3) Accessibility

Yet, to effectively participate in work and employment, the accessibility of workplaces and infrastructures, including public transport system and housing is a perquisite. Although both countries have legislation in place that promotes accessibility and the provision of reasonable accommodation and assistive devices, they often proof ineffective in practice. In Portugal, for instance, that legislation needs to be more strictly enforced and in Germany it needs to be extended to the private sector. Moreover, the process to have disability-specific needs addressed is highly bureaucratic and lengthy in both countries. To be more effective relevant legislation needs to be reviewed and duly enforced.

(4) Protection measures: Disability-specific protection measures, such as a protection period after vocational traineeships and a special dismissal protection for disabled employees, combat the misuse of existing support measures and can improve the employability of people with disabilities in the

open labour market. In contrast to the German legislation, the Portuguese traineeship scheme does not include a protection period after the financially supported training period. The collected stories show that many employers in Portugal do not make a job offer once the financially supported training period ends. In Germany employers have to reimburse part of the financial support if they do not offer employment after a financially supported period. Furthermore, the German dismissal protection ensures that disabled people are not subject to arbitrary behaviours. These German rules and practices seem promising in promoting and protecting the right to work and employment of people with disabilities and therefore their adoption in other contexts is recommended.

(5) Quota law: In both countries there is a quota law in place. However, the legislations in place in the two countries differ. In Portugal the quota law only applies to the public sector and there is no remedy in place if the quota is not fulfilled. In Germany the quota applies to both, private and public employers, and a compensation levy is in place which employers have to pay if they do not fulfil the quota. The analysis has shown that the quota law should (1) apply to both, the private and the public sector; (2) should be strengthened by a compensation levy which needs to be paid if employers do not fulfil their obligation under the quota; and (3) data about the effectiveness of the quota needs to be collected to enforce the implementation of the measure.

(6) Flexible economic support: The analysis has shown that many disabled people require flexible transitions between different employment measures, e.g. between sheltered and non-sheltered work. Social policies which do not support a flexible transition between different employment measures or between unemployment and employment, serve as a barrier to access the open labour market, as disabled people fear that they will lose their social entitlements, such as disability pensions, in the long run when they are getting employed in the open labour market. In addition, disability related costs often do not disappear once a person is employed. Thus economic support for

disability related expenses should be ongoing, even when a person is employed.

(7) **Closing sheltered workshops**: The German experience shows that sheltered employment increases the risk of feeling excluded and seems in many aspects not to comply with standards of dignified work conditions. Thus, the research results confirm the view that sheltered workshops are against the inclusive ethos of a human rights approach to disability (see chapter 3). However, the study also shows that people who have been traditionally employed in sheltered workshops need alternative support in the open labour market, for an extended period of time (according to their needs). In Germany, the measure of Supported Employment and the recently introduced "Job Budget" seems to change the present system in the right direction and therefore they can be promising practices for other countries to adopt.

9.1 Study limitations

Although this research was carefully prepared, I am aware of its limitations and shortcomings. Above all, the small sample size is not representative of the vast heterogeneity and intersectionality of the disabled population in Portugal and Germany. Due to the limited availability of resources, both in economic and temporal terms, it was only possible to give a small proportion of disabled people a voice. In the German sample no participants who are affected by visual impairments could be reached. Furthermore, for the present study only three human variables have been identified as relevant to the research, namely age, gender and the type of disability. The comparative analysis, thus, falls short in considering other human traits, such as race and migration backgrounds. Other studies (Pinto and Pinto 2017) indicate that these human traits further influence the lived realities of disabled people. As shown in chapter one, the definitions of disability vary across time, place, and culture (Degener 2006). Legal definitions and cultural perceptions of disabilities also vary between Portugal and Germany. Consequently, similar experiences in both countries might differ due to cultural and legal constraints. It is not claimed, however, that the findings from such a small-scale study can be generalised. More studies are needed that entail an emancipatory vision and that include the voices of people with disabilities.

Nevertheless, and despite all shortages, the study findings confirm other research (e.g. Hall and Wilton 2011; Sainsbury 2017; Kardorff 2010) which strengthens its external validity, and valuable promising policy directions could be identified from the results obtained.

9.2 Brave new world of work through the lens of disability

The thesis has shown that the present world of work, which promotes individual productivity and capitalist norms, the State becomes necessary to facilitate economic support and implement social policies that support the employment of social members who do not comply with hegemonic capitalist norms. As outlined in the theoretical part of this thesis, looking at the world of work through the lens of disability requires a new discourse in which values generally associated with waged labour, such as independence, self-reliance, productivity and mainstream work arrangements are altered. In Germany, inclusion companies, Supported Employment and the recently introduced "Job Budget" are a first step to create a "social labour market" (Arbeitskreis Arbeitsmarktpolitik 2018). At the core of these recently introduced measures lies not the aim to attain maximum individual productivity, but the goal to achieve a maximum of social participation through the provision of financial, personal and structural supports, that facilitate employment in the open labour market of people who have traditionally been excluded from mainstream work and employment.

The effect of these recently introduced measures needs to be monitored closely. The international disability human rights framework provides a standard for this assessment and a tool for empowerment and change, because it sets up obligations of progressive realization of rights on States that ratify Conventions and the monitoring obligation of the CRPD strengthens the voices of people with disabilities. Evaluation studies thus need to include the narratives of disabled people affected by the measures. People with disabilities, who due to their individual needs and capabilities, are unable to comply with the current world of work, might take a leading role in creating an inclusive and social labour market and in framing a new definition of social membership that is no longer based on the individual participation in paid work (Abberley 2002).

Nowadays, as work-centred societies are losing their central meaning (Beck 2001b), social policies that support and accommodate more just, equal and inclusive ontologies of work not only increase the inclusion of people with disabilities, but provide new perspectives for other disadvantaged groups such as persons with caring responsibilities, people with low education achievements, people with migration backgrounds and communication barriers and so on. Thus, such social policies might not only make a better society for people with disabilities to live but will initiate changes for a better society for all of us to live in (Sutherland 1981, 12).

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